The Need for Epistemic Reciprocity in Person-Centred Care: A Multi-method Qualitative Study

Myriam Dell’Olio

PhD in Medical Sciences

The University of Hull and The University of York

Hull York Medical School

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Abstract

Background – Person-centred care is a policy priority in the United Kingdom, yet people with long-term conditions report a deficiency in person-centred healthcare relative to their wishes and expectations. Whilst several factors contribute to this problem, recent work recognises a persisting reported failure of healthcare staff to give adequate credence to patients' knowledge work, which may contribute to worsening person-centred care. Therefore, I set out to answer the following research question: "What does an analysis of the knowledge work done by adults with chronic conditions in the context of their healthcare experiences tell us about changes needed to strengthen person-centred primary care?"

Methods – I adopted a multi-method qualitative design. This included a meta-ethnography of published research followed by primary data collection through individual interviews (analysed through interpretive phenomenological analysis) and focus groups (analysed through thematic analysis), which I integrated through an approach that focused on their complementarity.

Results – My empirical research described that the participants' knowledge work involves information seeking, experimentation and reflection, and leads to acquired experiential knowledge that is exclusive, unique and functional. The participants brought this knowledge to primary care settings to negotiate care, and successful negotiations unfolded through moments of active exploration, amplified listening, and reciprocal inquiry.

Discussion and conclusions – The person-centred clinical consultation is defined as a negotiated exploration of the patient's complex experience, grounded in both the patient's and the doctor's knowledge work, and that values and enhances the patient's learning journey. I therefore propose a new concept, epistemic reciprocity, as a principle that guides the clinical negotiation and fosters the co-creation of new knowledge of patient experience and need through the interactive knowledge work of patient and doctor. In considering epistemic reciprocity as a core component of successful person-centred care, I describe the implications for future education, professional practice, and research.

Contents

List of abbreviations

Abbreviation	**Meaning**
COPD	Chronic Obstructive Pulmonary Disease
EBM	Evidence-Based Medicine
ENTREQ	Enhancing Transparency in Reporting the Synthesis of Qualitative Research
FG	Focus Group
GP	General Practitioner
IPA	Interpretive Phenomenological Analysis
JBI	Joanna Briggs Institute
NHS	National Health Service
PCC	Person-Centred Care
PPI	Patient and Public Involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
REC	Research Ethics Committee
SES	Socioeconomic Status
UK	United Kingdom
WHO	World Health Organisation

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Chapter 1 – Introduction

This PhD positions itself in the context of the changing face of primary care, where long-term conditions are on the rise, traditional roles and services are being challenged, and patients' preferences and expectations are evolving (Choi *et al.*, 2015). In such a dynamic context, a paradigm shift from disease-focused to person-centred models of healthcare has long been recognised (World Health Organization, 2005), as it has been proposed that people with long-term conditions would benefit from more person-centred approaches (Miles and Asbridge, 2017).

However, people with long-term conditions still report a deficiency in person-centred healthcare relative to their wishes and expectations (Blendon, *et al.*, 2003; Care Quality Commission, 2012; Silver, 2018). In this chapter, I explore reasons for this reported lack of person-centred care, and present my focus on one underexplored area, namely the processes involved in reconciling different viewpoints. If we are to achieve 'shared decisions' between patient and professional, then both parties need to understand the other's perspective and so negotiate a shared understanding (Coulter and Collins, 2011; Denford *et al.*, 2014). Yet, patients continue to complain about healthcare professionals not listening to them (Berman and Chutka, 2016), hence remaining unaware of, or unresponsive to, the patients' values and preferences, preventing truly collaborative decisions (Levinson *et al.*, 2010). To address the challenge of reconciling patients' understanding of illness with professional/health service understanding and priorities, we must consider both parties' knowledge work as they create, shape, and share those understandings.

Knowledge work describes the search for, evaluation of, and use of knowledge for everyday work/activity, with the potential for knowledge creation (Quinlan, 2009). An example of knowledge work is the work done by a person with a chronic condition as they apply their experiential knowledge acquired by adjusting medication doses (or the doctor's instructions on how to adjust medication doses) to their medication until they find the dose that works best for them (new knowledge). In the context of a clinical consultation, knowledge work for both health professional and patient refers to the use of patient narratives, evidence, and professional understanding to create clinical decisions. Some research has looked at the knowledge work of healthcare professionals (Snyder-Halpern *et al*., 2001; Brooks and Scott, 2006; Quinlan, 2009), but little work has looked at the knowledge work of patients during clinical consultations.

My PhD thus aims to understand the knowledge work of people with long-term conditions in the context of their healthcare experiences, and to reflect on its role in person-centred primary care.

1.1 Living with chronic illness – A new public health challenge

Western health systems are currently facing a surge in chronic illness in aging populations (Barnett *et al*., 2012). Health initiatives and medicine's improved ability to prevent death from disease played a role in the increase of people's life expectancy, and so contributed to rising numbers of older people and therefore prolonged time living with long-term conditions (Fuller, 2016). Now, chronic conditions and their management form the biggest challenge for modern health systems, as one in three adults globally suffers from multiple chronic conditions (Hajat and Stein, 2018). In the United Kingdom, estimates of prevalence of people with multiple chronic conditions range from 16% to 58% (depending on the number of chronic conditions included in the estimate) (Salisbury *et al*., 2011), and the challenge is predicted to increase in the future (Kingston *et al*., 2018).

Over the past few decades, modern healthcare has developed and incorporated innovative approaches that foster processes of treatment and diagnosis of these conditions (Lorenzetti *et al*., 2012). These processes are based on the biomedical model of health, an approach to healthcare founded on the idea that each disease has a single cause and stems from cellular abnormalities (Wade and Halligan, 2004). In this context, the knowledge work used by professionals to deliver this care is built on the principles of evidence-based medicine (EBM) to inform best practice (Walsh and Gillett, 2011). EBM has been defined as "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett *et al*., 1996, p. 71). The rise of EBM is considered to have fostered clinicians' awareness to keep up-to-date and to take into account the scientific method for decision-making and clinical effectiveness (Worrall, 2002). However, whereas the EBM approach works best for single disease models of practice and fostered the development of several guidelines for the treatment of single diseases, the need to design new forms of clinical guidelines to inform the treatment of chronic multimorbidity has been pointed out (Guthrie *et al*., 2012).

Therefore, we see a growing mismatch between the health needs of populations (the rising numbers of people with chronic conditions) and the priorities of health services, focusing on the adoption of single-disease models. This continued focus on a biomedical model was found to be insufficient to face the described new public health challenge (Alonso, 2004). With growing recognition that chronic conditions were not only affected by biological processes alone, but rather by a combination of biological, psychological, and social factors (Santrock, 2007), biomedical approaches alone were missing important aspects of chronic conditions. Furthermore, according to Tinetti and Fried (2004), the biomedical single-disease approach fostered the development of a multitude of guidelines that could end up contributing to the patients' treatment burden, even more so when the advice or guidelines given to the patients were contradictory (Sav *et al*., 2013). Whereas primary care was identified as the key to achieve health for all, as well as an essential part of social and economic development (World Health Organization, 2000), this incongruity puts significant strain on resource-limited healthcare settings, to the point that the rise of noncommunicable diseases has been identified by the World Health Organization (WHO) as one of the major challenges for development of the twenty-first century, if not an actual "slow motion disaster" (World Health Organization, 2017, p. 95).

A proposed policy response to these emerging challenges has been for more comprehensive and effective approaches to clinical care (Iacobucci, 2014). The WHO called for a "paradigm shift" in healthcare, namely a transition from an acute, single disease care model to a chronic disease care model, believing that the latter focuses more on patient-centred care, and highlighting its importance for healthcare policies (World Health Organization, 2005, p. 3). This perspective has been recognised by national governmental policies in the UK, where patient-centred care has become a policy priority. Examples of this are the NHS goals to develop good practice on patient-centred planning and to support people to manage their own health and make informed choices about it (NHS England, 2014a).

Despite this commitment at national and international levels, several studies found that people with chronic conditions' expectations regarding person-centred healthcare are not always met, for example because of limited involvement in decision making (Ahmad, *et al.*, 2014; Goodwin, *et al.*, 2011) or lack of a written care plan (NHS England, 2015). Understanding why and what we can do about this decline was the starting point of my PhD.

In this chapter, I start by introducing person-centred care, presenting common barriers to its implementation, and so demonstrating my focus on knowledge work. I highlight how and why these barriers are often due to a lack of integration of different types of knowledge and perspectives into clinical consultations, and so propose this as a novel area of study to find solutions. Then, I describe how (patient) knowledge has been conceptualised over time, and present epistemic injustice as the conceptual framework chosen for my study to look at the issue of knowledge integration in clinical settings.

1.2 Person-centred care and the management of chronic conditions

In recognition of the challenges posed by the rise in long-term conditions described earlier in this chapter, we see a shift in emphasis on healthcare models that acknowledge not only the person's disease, but also his or her illness experience. More person-centred approaches have been suggested, as they recognise the biopsychosocial dimensions of health, prioritise the person's subjective experiences, and involve patients in decision-making processes (Burton *et al*., 2017).

Before we can understand why people with long-term conditions report a lack of person-centred care, we need to clarify what we mean by person-centred care. Therefore, in this section, I provide an overview of the meanings and definitions of the concept of person (and patient) -centeredness, and then of the barriers to its implementations described from a patient perspective.

1.2.1 The issues of defining and implementing person-centred care

The concept of person-centeredness has been widely studied, analysed, and conceptualised over the last twenty years (McCormack and McCance, 2006; Leplege *et al.*, 2007; Morgan and Yoder, 2012; Scholl *et al.*, 2014), yet significant ambiguities remain in practice and policy. The concept of patient-centred care builds on the work of the Balint (Balint, M., 1955; Balint, E., 1969), who suggested a need to adopt "patient-centred care", an alternative way of medical thinking that focuses not only on discovering localizable illnesses, but also on examining the patient as a whole. However, defining what this means in practice has proven challenging.

Definitions vary, and the term has been used interchangeably with several other expressions (examples being patient-centeredness, relationship-centeredness, client-centeredness, and family-centeredness). Studies that focused on either person or patient -centeredness have identified several key aspects of the concept. I provide a brief overview of some of these studies in table 1.1. Whilst there is much overlap between the concepts described, no single conceptual model/definition has been identified. So, for example, there is overlap between Mead and Bower's five dimensions (2000) and Scholl's and colleagues' (2014) four principles of patient-centred care, as in both cases they highlight the importance of the adoption of a biopsychosocial perspective. On the other hand, whereas Mead and Bower's dimensions all referred to the doctor-patient relationship, this was only one of the four principles of patient-centred care described by Scholl *et al.*, who also included the involvement of the patient's family and friends as an aspect of patient-centred care. As regards the characteristics of person-centred care, Morgan and Yodler (2012) emphasised the provision of tailored, holistic care while also empowering the person to participate in decision making, while McCormack (2004) emphasised the importance of a caring context of care that nurtures individual personhood. Still, there is also overlap between definitions of patient and person -centred care, as for example both McCormack (2004) and Mead and Bower (2000) wrote that patient/person -centred care is about knowing the person, referring to both the patient and the health professional.

Table 1.1. Definitions of person and patient -centred care.

Authors	**Concept described**	**Methodology**	**Characteristics of patient (or person) -centred care**
Mead and Bower, (2000)	Patient-centred care	Literature review	Five conceptual dimensions: biopsychosocial perspective, sharing power and responsibility, therapeutic alliance, patient-as-person, and doctor-as-person.
Scholl, *et al*., (2014)	Patient-centred care	Concept analysis	Four principles: essential characteristics of the clinician, clinician-patient relationship, patient as a unique person, and biopsychosocial perspective.
Morgan and Yodler, (2012)	Person-centred care	Concept analysis	Four attributes: holistic, individualized, respectful, and empowerment.
McCormack, (2004)	Person-centred care	Literature review	Themes: knowing the person, values, biography, relationships, seeing beyond immediate needs, and authenticity.

Dewing (2008) observed that frameworks for the use and implementation of person-centred care in practice and policy have been developed with haste, leading to its philosophical and theoretical bases being overlooked. In addition, the confusion and disagreement around the meanings of the concepts related to person-centred care can have consequences for clinical practice (Castro *et al*., 2016). For instance, in the United Kingdom, notwithstanding the commitment of successive governments to person-centred care, patient surveys show that patients believe that healthcare professionals are not delivering nor implementing person-centred care in a meaningful way (Mathers and Paynton, 2016). Patients describe that they wish to be more involved in their own care, but are receiving care that does not meet their perceived needs (Young and Roberts, 2011; NHS England, 2014b). According to Miles and Asbridge (2017, p. 4), although there have been attempts at increasing patient-centeredness in the UK, they have often been limited to

> “the administration of patient satisfaction questionnaires, the employment of patient-reported outcome measures, and the use of decision aids as part of shared clinical decision making.”

Reasons for this lack of person-centred care are varied. In general practice, several challenges to the successful implementation of person-centred care have been identified, namely (1) lack of integration between different services, (2) lack of leadership, (3) workforce shortages, (4) lack of time and resources, and (5) traditional attitudes and behaviours (Farrar *et al*., 2014).

Furthermore, the healthcare sector is now “overwhelmed by a crisis in accessibility” (Hogg *et al*., 2008, p. 308), with general practice being affected by a demand that has outstripped the available resources (Hawkes, 2016). Whereas general practice has been identified as the most suited service for the care of long-term conditions (Lawrence, 1988), NHS spending on general practice has decreased over the last decade, with only 8,1% of the UK NHS budget being spent on it in 2017 (British Medical Association, 2020).

To summarise, issues known to contribute to a lack of person-centred care include a range of professional, patient and context factors such as lack of staff, time, and equipment (West *et al*., 2005), patient-doctor communication issues (Vennedey *et al*., 2020), and discrepancies between patients’ and doctors’ viewpoints (Gluyas, 2015). In this context, research has increasingly recognised the need to focus on the patients’ perspective on person-centred care (Ferguson *et al*., 2013; Rathert *et al*., 2015).

Still, policy and organisational changes might have attempted to strengthen and improve the delivery of person-centred care potentially in ways that did not always reflect the patients' own views and priorities. Further research has highlighted the impact of evidence-based medicine in overshadowing the patients' narratives and values in current health systems (Schulte, 2017), with the biomedical explanation and management of illness being privileged over patient or indeed professional experiential accounts (Reeve, 2010).

Nonetheless, evidence highlights that patients engage in knowledge work to make sense of their illness and experiences (Carel, 2007). However, as described earlier in this chapter (see page 9), part of that work requires them to negotiate their perspective with the perspective of health professionals, who in turn engage in their own knowledge work. When these negotiations fail, and the patient's narratives and knowledge work are overshadowed by different types of knowledge, patients complain about a reported failure of person-centred care. Whilst it is recognised by policymakers and researchers alike that certain aspects of care can be deleterious to people's experiences, patients' complaints about failure to listen to them persist, and have one thing in common, namely health professionals' scarce sensibility to the patient's testimony as a person with a valuable illness experience (Kidd and Carel, 2017).

Therefore, to strengthen person-centred care, we need to consider new approaches to the knowledge work of people living with chronic conditions in healthcare settings.

To critically examine the patients' knowledge work in the context of people's healthcare experiences, I use the lens of epistemic injustice, which describes how people can be wronged in their capacity as knowers (Fricker, 2007). However, in seeking to appreciate if, how and why different forms of knowledge are valued and used within different places in society, we first need to turn to the discipline of epistemology – the study of knowledge and how it is justified (Audi, 2011). Therefore, before understanding how epistemic injustice comes to be, we need to understand that there are different ways to define and evaluate (patient) knowledge. I write more about this in the next section.

1.3 Exploring the concept of (patient) knowledge

As explained in the previous section, person-centred healthcare involves a negotiation between patients' and professionals' perspectives when making sense of illness experience, and so decide on the condition's management. To understand this negotiation, we must first recognise how different parties define legitimate (i.e., 'best'/'correct') knowledge.

Scientific practice and philosophy recognise an array of different approaches to generating and valuing different types of knowledge (Bunniss and Kelly, 2010; Fraser *et al*., 2019). In modern medical practice, however, a single approach (i.e., the knowledge work recognised within evidence-based medicine) is currently privileged, with other approaches relegated to a lesser status (Evans, 2003). One form of knowledge that is often relegated in modern medical practice is the patient's knowledge (Cronje and Fullan, 2003). Still, as I explain in the next section, the definitions and classifications of knowledge are not unambiguous, ultimately leading to a variety of stances and interpretations on what constitutes legitimate knowledge.

1.3.1 Understanding different types of knowledge

Knowledge is defined as "the information, understanding and skills that you gain through education or experience" (Oxford Advanced Learner's Dictionary, 2021). According to Biggam *et al*. (2001) knowledge can be empirical (i.e., based on experience) or rationalistic (i.e., based on thought processes) but, in all cases, it must distinguish truth from falsehood. However, over the course of time, knowledge has been defined in different ways: as a state of mind (i.e., a state of knowing and understanding), a process (e.g., the process of applying expertise), an object (e.g., something to be stored and manipulated), and as a capability (e.g., the capability to influence action) (Alavi and Leidner, 2001).

One of the classifications of knowledge that have been widely adopted in the field of healthcare sciences while being borrowed from that of organisation science is the distinction between explicit and tacit knowledge. While explicit knowledge is formal, systematic, and easily communicated, tacit knowledge is personal, deeply rooted in action, and contextual, hence being difficult to communicate (Nonaka, 1994). In the healthcare sciences, explicit knowledge can be exemplified by scientific evidence, whereas an example of tacit knowledge is the know-how and intuitive judgement of an expert practitioner (Patel *et al*., 1999; Kothari *et al*., 2012). It is worth mentioning that Nonaka (2007) does not value one type of knowledge more than the other, but says that the combination of the two leads to knowledge creation in any organisation.

Understanding types of knowledge through hierarchies is also possible, and was proposed by Russel Ackoff (1989), who conceived a knowledge pyramid at the top of which lay wisdom, followed by knowledge, information, and data. Although some of these terms have been occasionally used interchangeably (e.g., data and information, or information and knowledge) they were originally intended to have different meanings (Baskarada and Koronios, 2013). Starting from the bottom of the hierarchy, data are defined as symbols that are the product of observation but have no meaning without context (Groff and Jones, 2012). Information is described as data organised meaningfully and in a useful way (Laudon and Laudon, 2007). Then, knowledge is information that can be used with a purpose, or that can be applied to a problem (e.g., a series of instructions) (Turban *et al*., 2005. The distinction between knowledge and information is not clear-cut, as it has been pointed out that what is knowledge to someone may be considered information by someone else (Alavi and Leidner, 2001). Finally, wisdom has been defined as accumulated knowledge that brings about the ability to apply concepts to different situations, but also to think critically and practically (Jashapara, 2004; Jessup and Valacich, 2008). As Bernstein (2009) explained, the synthesis and compound of different types of knowledge (e.g., the patient’s knowledge of their own illness experience, and the clinical knowledge of the doctor) can lead to wisdom that, according to Ackoff (1989), is essential for the pursuit of valued goals.

In a context in which there is no one definition of knowledge, it becomes even more challenging to understand whether what people with chronic conditions learn throughout their illness experience can be defined ‘knowledge’, and where that knowledge would locate itself in the wider epistemological debate. I elaborate more on patient knowledge in the next section.

1.3.2 The characteristics of patient knowledge

The concept of patient knowledge has its roots in the wider discourse around experiential knowledge. This was introduced by Borkman (1976), who defined it as truth learned from personal experience, but also 'know-how', as opposed to professional knowledge, which was considered a more widely accepted source of truth. The tension between personal experience and professional knowledge was further highlighted by Blume (2017), who wrote that it is still unclear how patient experience is conceptualised into knowledge, and that patient experience is recognised as knowledge only when it does not deviate too much from medical knowledge and assumptions.

Over time, people's understanding of illness, health and medical care has been labelled differently, from 'beliefs' to 'lay knowledge' (Williams and Popay, 1994). This is particularly true in the field of medicine and healthcare, where the role and usefulness of patient knowledge have been widely discussed, with a growing consensus in the health and social sciences towards its incorporation into clinical encounters – for example, through a recognition that patients can be experts (Arksey, 1994), or through the development of guidelines for clinicians to facilitate patient involvement and shared decision-making (Hoffmann *et al.*, 2014).

Pols (2014, p.75) defined patient knowledge as a form of knowing in action from which techniques to deal with disease are derived, but also calls it "messy" from an epistemological point of view, as it involves different techniques and materials. Pols' definition of patient knowledge as knowing in action is in line with Alavi's and Leidner's (2001, p. 14) proposed definition of knowledge – "a justified belief that increases an entity's capacity for taking effective action" –, as "effective action" may be problem-solving activities in the daily context of living with a long-term condition. This resonates with Carel's (2007) observations that people with an illness learn new ways to look at the world and cope with their conditions through reflection. According to Merleau-Ponty

(1962), illness itself triggers reflection, and through a person's reflexive consciousness, their symptoms become objects of scrutiny (Sartre, 1966).

In time, patient knowledge has been increasingly recognised as expertise by policymakers in the UK as well, who defined it an "untapped resource" for the management of chronic disease (Department of Health, 2001, p. 33). The General Medical Council (GMC) ethical guidance for doctors also established that meaningful dialogue is based on the exchange of information that is relevant to the patient, and that not listening to patients can cause them serious harm (GMC, 2020). Still, several health professionals' attitudes towards expert patients were negative, as the very expression "expert patient" was considered to be prone to provoke hostility in doctors (Shaw and Baker, 2004). In the UK, the limited success of the Expert Patients Programme national policy was found to be partly due to a reported failure of physicians to give due attention to the perspectives and work of patients themselves (Rogers, 2009). Therefore, even in a context in which patient knowledge has been recognised as valuable expertise by policymakers and researchers alike, it can still be discredited by healthcare professionals in healthcare settings, thus inhibiting person-centred care (Rogers *et al.*, 2005), with a potential to create epistemic injustice (Buchman *et al.*, 2017). I describe this epistemic injustice in more detail in the next section.

1.4 Introducing and defining epistemic injustice

In the previous section, I have described how different types of knowledge can be defined and compared to each other. Then, I have reported that whereas patients' knowledge provides them with ways to cope with their conditions, and has been increasingly recognised over time, their knowledge work often receives limited attention in modern medical practice.

However, in the context of delivering person-centred care – care that understands and tailors care to an individual and their circumstances –, privileging scientific knowledge means undermining patient's illness knowledge, a process which can be considered a form of injustice. This injustice is recognised within the work of Fricker (2007) as a process called 'epistemic injustice'.

In this section, I consider whether looking at epistemic injustice in healthcare settings can help explain people's perceived deficiency in person-centred healthcare relative to their expectations. I start by providing an overview of the concept of epistemic injustice, and then reflect on how issues of epistemic injustice are problematic for the advancement of person-centred care.

1.4.1 Epistemic injustice in healthcare settings

Epistemic injustice describes situations in which a person is wronged in their capacity as a 'knower', hence being unjustly prevented from receiving or sharing knowledge (Fricker, 2007). According to Fricker (2007), epistemic injustice can occur when someone's credibility is discredited because of prejudice and negative stereotyping (testimonial injustice), or when some people are excluded from activities that shape how their society understands concepts (hermeneutical injustice). For instance, testimonial injustice may occur in healthcare settings when a doctor ignores what a patient is saying because s/he assumes that the patient does not have the capacity to provide relevant information. On the other hand, hermeneutical injustice in healthcare settings can be exemplified by patients' inability to understand and address their own illness experience due to limited involvement in medical research, leading to a lack of patient-derived concepts in clinical settings, which patients could have used to codify and express their feelings.

This concept has been used to understand patients' negative experiences of healthcare. For instance, patients have been found to be victims of epistemic injustice due to some health professionals' negative prejudices or presumptions about patient knowledge (Blease *et al.*, 2017). In particular, some patients see their credibility downgraded because of wrongful stereotyping (i.e., testimonial injustice), for example ill people that are considered to be so "dominated by their illness" that their capacity to report on their experiences is perceived as downgraded (Kidd and Carel, 2017, p. 179). In this case, epistemic injustice occurs as patients' accounts are given less credibility than deserved. A reflection on hermeneutical injustice in healthcare settings can be found in another study by Carel *et al*. (2017), who wrote that it could lead to a lack of interpersonal care because of a fundamental lack of knowledge amongst health care professionals of patients' perspectives and concepts such as that of illness experience.

More recently, epistemic injustice has been observed and described by other authors in different settings and in relation to different conditions, some examples being male breast cancer, mental health, and language barriers in healthcare (Peled, 2018; Grim *et al*., 2019; Younas, 2020), indicating that the presence and relevance of epistemic injustice in healthcare settings is being increasingly recognised and discussed by researchers. Some examples of studies about epistemic injustice in healthcare settings are presented in table 1.2.

Table 1.2. Examples of studies about epistemic injustice in healthcare settings.

Study title *(and authors)*	**Application of epistemic injustice**
The Legitimacy of User Knowledge in Decision-Making Processes in Mental Health Care: An Analysis of Epistemic Injustice. *(Grim, et al., 2019)*	Epistemic injustice is used as a framework to understand barriers involved in legitimizing user knowledge in decision-making processes.
Epistemic injustices in clinical communication: the example of narrative elicitation in person-centred care. *(Naldemirci et al., 2021)*	Epistemic injustice is used as the study's theoretical framework for the analysis of narrative elicitation during clinical consultations.
Language barriers and epistemic injustice in healthcare settings. *(Peled, 2018)*	Epistemic injustice is used to describe the ethical issues that stem from the impact of language barriers on healthcare provision.
Epistemic Injustice in Health Care Professionals and Male Breast Cancer Patients Encounters. *(Younas, 2019)*	Epistemic injustice is used to demonstrate how male breast cancer patients experience systemic stigmatisation and marginalisation in healthcare settings.

Bogaert (2020, p. 2) recognised a relation between epistemic injustice and person-centred care, as she pointed out that person-centred programmes keep focusing on health institutions' rather than patients' perspectives. Therefore, she suggested that rectifying epistemic injustice through the adoption of patient-derived concepts is paramount for the advancement of person-centred care (Bogaert, 2020). The need to reflect on the link between person-centred care and epistemic injustice is also prompted by the finding that people with chronic conditions in the United Kingdom report decreased satisfaction with patient-centred care indicators such as listening, explaining, and decision-making (Redding and Hutchinson, 2017), which involve using knowledge or relate to knowledge to some extent.

To summarise, in this section I introduced the concept of epistemic injustice, and described how patients' voices can be ignored (i.e., through testimonial and/or hermeneutical injustice). I presented instances of epistemic injustice in healthcare settings identified by other authors, and acknowledged the increasing recognition of epistemic injustice in healthcare research. Finally, I highlighted the link between epistemic injustice and person-centred care; not only epistemic injustice can wrong people with long-term conditions because it happens through wrong stereotyping or lack of involvement, but also because it prevents the adoption of tailored, whole person healthcare by undermining patients' knowledge work.

1.5 Chapter summary

In this introductory chapter, I have discussed the meaning and role of person-centred care in the light of the current public health challenge posed by chronic conditions. I have argued that person-centred care is not being implemented meaningfully according to people with long-term conditions. Firstly, because there is confusion around what person-centred care means, and therefore uncertainties and discrepancies in what to do to implement it. Secondly, because of how knowledge is valued in healthcare settings. Specifically, I have described examples of epistemic injustice in healthcare settings – related to both the privileging of some types of medical knowledge, and the failure to recognise the distinct epistemic value of patient knowledge. In this thesis, I consider whether we can improve person-centred care by preventing this epistemic injustice.

My overall thesis’ aim is to understand what an analysis of the knowledge work done by adults with chronic conditions in the context of their healthcare experiences tells us about changes needed to strengthen person-centred primary care. In the next section, I explain the aims and objectives of my doctoral research.

1.6 Thesis aims and objectives

At the start of my PhD, I set out to conduct a study to understand the knowledge work of people with long-term conditions in the context of their primary healthcare experiences, using epistemic injustice as a framework. This goal was a response to perceived lack of person-centred care as described by people with long-term conditions, and the increasing reports of epistemic injustice in healthcare settings as presented in the previous sections. I decided to focus mainly on general practice settings, which were considered crucial for the treatment of chronic conditions, yet challenged from a person-centred perspective.

With this goal in mind, I formulated the main research question as follows:

> *What does an analysis of the knowledge work done by adults with chronic conditions in the context of their healthcare experiences tell us about changes needed to support person-centred primary care?*

With healthcare experiences, I refer to the participants’ daily experiences of managing their illness, as well as their experiences of attending healthcare services to access the diagnosis and/or treatment of their conditions. As a starting point, I decided to carry out a qualitative evidence synthesis in order to gain an overview of the aspects of person-centred care that matter to people with long-term conditions. Then, I set out to understand and describe their knowledge work and its role during primary care consultations. Thus, in order to answer the main research question, I set three main study aims:

- To develop a critical understanding of the essential aspects of person-centred care from the perspective of people with long-term conditions.

- To systemically describe the knowledge work of people with long-term conditions in the context of their healthcare experiences.

- To critically consider whether changes in approaches to understanding and supporting patient knowledge work can foster the enhancement of person-centred care.

In order to achieve these aims, I developed the following objectives:

- To undertake a meta-ethnography of published research on the healthcare experiences of people with long-term conditions.

- To conduct in-depth interviews and focus groups to explore the knowledge work of people with long-term conditions in the context of their illness and healthcare experiences.

- To integrate interviews and focus groups data to explore multiple aspects of the patients’ knowledge work and reflect on changes needed to strengthen person-centred care.

I describe how I planned to achieve these objectives in Chapters 2 and 3, as outlined in the next section.

Thesis outline

In this thesis, I explore the knowledge work of people with chronic conditions through the lens of epistemic injustice in order to get an understanding of changes needed to support person-centred primary care. I use the expression person-centred care (with ‘care’ referring to ‘healthcare’), because my PhD has focused on people (rather than exclusively patients) and their experiences.

In this chapter, I have provided an overview of the concept of person-centred care and its relevance to the current public health challenge posed by rising numbers of people living with chronic conditions. I introduced the main problem, namely that person-centred care is not being implemented meaningfully according to people with long-term conditions. Then, I looked at this problem through the lens of epistemic injustice, focusing on the knowledge of patients and on its limited integration in healthcare settings. Finally, I presented the aims and objectives of this study. In Chapter 2, I present the methodology and the findings of a qualitative evidence synthesis that I conducted to understand the essential aspects of person-centred care from the perspective of people with long-term conditions. In Chapter 3, I describe the multi-method qualitative approach that I applied to the collection, analysis and integration of individual interviews' and focus groups' data. Then, in Chapters 4 and 5, I report the findings of the integration of in-depth interviews and focus groups; in particular, Chapter 4 focuses on the participants' knowledge work and on the characteristics of the knowledge it generates, whereas Chapter 5 describes the use of this knowledge in primary care settings, and the moments in (person-centred) clinical consultations that allowed for the integration of patient knowledge. In Chapter 6, I reflect on the person-centred clinical consultation as a negotiated exploration of the patient's complex experience, grounded in both the patient's and the doctor's knowledge work, and that values and enhances the patient's learning journey. I defend my proposal of the novel concept of epistemic reciprocity as a core element of person-centred care, and a principle that guides the clinical negotiation and fosters the co-creation of new knowledge of patient experience and need through the interactive knowledge work of both patient and doctor. Then, I conclude by considering my study's implications for research, education, and practice.

Chapter 2 – How people with long-term conditions understand person-centred care: A meta-ethnography

The first aim of my PhD was to develop a critical understanding of the essential aspects of person-centred care from the perspective of people with long-term conditions. I decided to achieve this aim by investigating the healthcare experiences of people with long-term conditions through a systematic review of published literature. This patient derived understanding of person-centred care would then inform the next stages of my research.

My first step was to systematically synthesise what we already know about patients' views of person-centred care in the context of their healthcare experiences. This would be best achieved through a systematic review of qualitative studies. However, there are several approaches to the synthesis of qualitative literature. Examples include critical interpretive synthesis, meta-study, thematic synthesis, and meta-ethnography (Tong *et al*., 2016). As critical interpretive synthesis is particularly suited to the synthesis of explanatory theories (Dixon-Woods *et al*., 2006), and my aim was more exploratory instead, I excluded it as a potential approach to my review. Meta-study, on the other hand, is an approach that focuses on synthesising theories, methods, and findings (Paterson *et al*., 2001). However, since synthesising theories and methods was not essential to achieve my research aim of exploring patients' experiences, I excluded meta-study as well. Another approach to the integration of findings of multiple qualitative studies is thematic synthesis (Thomas and Harden, 2008). Still, since thematic synthesis was developed in response to a need to synthesise studies on interventions (e.g., their acceptability, effectiveness, and appropriateness), I decided to adopt a different approach that would be better suited to the exploration of patient experiences. Therefore, I eventually opted for meta-ethnography (Noblit and Hare, 1988), because it is particularly suited to the exploration of people's experiences, and to the development of a conceptual understanding of a phenomenon (Toye *et al*., 2013).

Although meta-ethnography can be conducted in different ways (Britten *et al*., 2002; Malpass *et al*., 2009) it consists of seven phases of search and analysis.

These are (1) getting started, (2) deciding what is relevant, (3) reading the studies, (4) determining how the studies are related, (5) translating studies into one another, (6) synthesizing translations, and (7) expressing the synthesis. In this chapter, I present the details of the methodology and the findings of this qualitative evidence synthesis, which has been published on the European Journal of Person-Centered Healthcare (a pre-proof version of the paper is available in appendix A, page 203).

2.1 Getting started

Meta-ethnography starts with the identification of a research topic that can be informed by a qualitative evidence synthesis (i.e., a systematic review of qualitative literature). The research topic that I decided to study involved the (person-centred) healthcare experiences of people with long-term conditions in primary and secondary care settings. For this meta-ethnography, I chose to include both primary and secondary care settings because evidence highlighted a lack of personalised care across different healthcare settings, from specialised to residential and primary care settings (Redding and Hutchinson, 2017).

Therefore, I formulated the research question of my qualitative evidence synthesis as follows:

- What are the essential elements of a person-centred healthcare system as described by the experiences of patients?

After identifying a research topic, the following step was to decide what information would be relevant to its investigation.

2.2 Deciding what is relevant

In this second phase, I had to decide what information was relevant to answer the research question. I did this through a series of steps: developing a search strategy, deciding which databases to use, defining a list of eligibility criteria for inclusion in the review, and eventually selecting the studies to include in the review.

As a first step, I wrote a systematic review protocol, informed by the ENTREQ (Enhancing transparency in reporting the synthesis of qualitative research) guidelines of best practice (Tong *et al*., 2012). I registered the systematic review protocol online on PROSPERO (see crd.york.ac.uk/prospero/, registration number CRD42018094380).

I conducted a search of the following databases: ASSIA (Applied Social Sciences Index and Abstracts), BNI (British Nursing Index, now known as British Nursing Database), CINHAL Plus, the Cochrane Library, Embase, PsycINFO, PubMed and Medline, Scopus, and Web of Science. I also included the Cochrane Library to check whether there were any reviews similar to the one that I was about to conduct. Finally, I searched WorldCat, Grey Literature Report, the INVOLVE Libraries, and OpenGrey in order to retrieve any relevant grey literature.

The development of the search strategy was informed by the research question and by other systematic reviews of qualitative studies about the experiences of people with long-term conditions. I employed a combination of subject heading and keyword searching depending on the database. Grey literature databases did not allow for the use of elaborate search strategies or subject heading, so I only used keyword (free text) searching in those cases.

After developing the search strategy, I tested it, and revised it with input from both my supervisors (Prof. Joanne Reeve and Dr. Julie Seymour) and the University of Hull’s information specialists (Skills team). I included the search strategies in Appendix B (page 232). I conducted the search between February 2018 and March 2018, and updated it in September 2019 (excluding grey literature databases). I identified additional records through reference list checking.

I drew a list of eligibility criteria (table 2.1) prior to the beginning of the search, though I amended them slightly during the titles and abstracts screening phase; amendments aimed to narrow the review’s scope (e.g., excluding telecare studies).

Table 2.1. Eligibility criteria for inclusion in the qualitative evidence synthesis.

<u>Inclusion criteria</u>	***<u>Exclusion criteria</u>***
- Qualitative studies that involve adults (>18 years old) with physical and/or mental chronic conditions; - Studies that acknowledge person or patient-centred care; - Studies published in English; - Studies conducted in developed countries; - Studies with mixed-methods designs with a substantial qualitative component; - Studies conducted in primary or secondary care settings; - Empirical studies (including reviews of qualitative studies).	- Studies presenting exclusively quantitative data and methods; - Meta-analyses, book reviews, study protocols, conference proceedings, commentaries, and systematic reviews of quantitative studies; - Studies about: * Complementary medicine * Illness (not healthcare) experience * Other groups (e.g., caregivers, health professionals) * Specific groups (e.g., sex workers, veterans) * The creation, validation, or assessment of a model, intervention, toolkit, and so forth * Telecare and home-based care * Care delivered by students/trainees - Studies involving more than two stakeholder categories (e.g., patient, carers, and providers), or presenting the findings in an unclear way (e.g., “the participants said”); - Exclusively methodological and/or theoretical studies.

Inclusion criteria aimed to identify relevant empirical qualitative studies written in English and conducted in developed countries (for ease of comparison, and prevalence of long-term conditions), or mixed-methods studies in which qualitative data were prioritised (Archibald *et al.*, 2015). I determined such studies by looking at the contribution of the qualitative and quantitative methodologies to the studies' aims/research questions; at the depth of the methodological descriptions of different methods (i.e., theoretical and procedural details); and by comparing length of quantitative and qualitative results sections. Therefore, only mixed methods studies with qualitative and quantitative findings presented separately were eligible for inclusion.

Exclusion criteria aimed at excluding topics that could warrant a separate review (such as telecare and home care), studies that had a different focus (e.g., illness instead of healthcare experience), and studies about out-of-the-ordinary healthcare practices (e.g., care delivered by students, or the implementation or assessment of a specific intervention).

I transferred the search results (i.e., studies' references, titles, and abstracts) to a dedicated EndNote library. Then, I screened all the records against the eligibility criteria with a second reviewer (Sophie Pask, a fellow PhD student). We did this independently, though we met regularly to compare our decisions and address any disagreements. Sometimes, minor doubts persisted even after discussion, but were solved with the help of my academic supervisor (Prof. Joanne Reeve), who acted as a third reviewer.

I developed two flow diagrams (see figures 2.1 and 2.2) documenting the screening process in accordance with the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) guidelines (Moher *et al.*, 2009) .

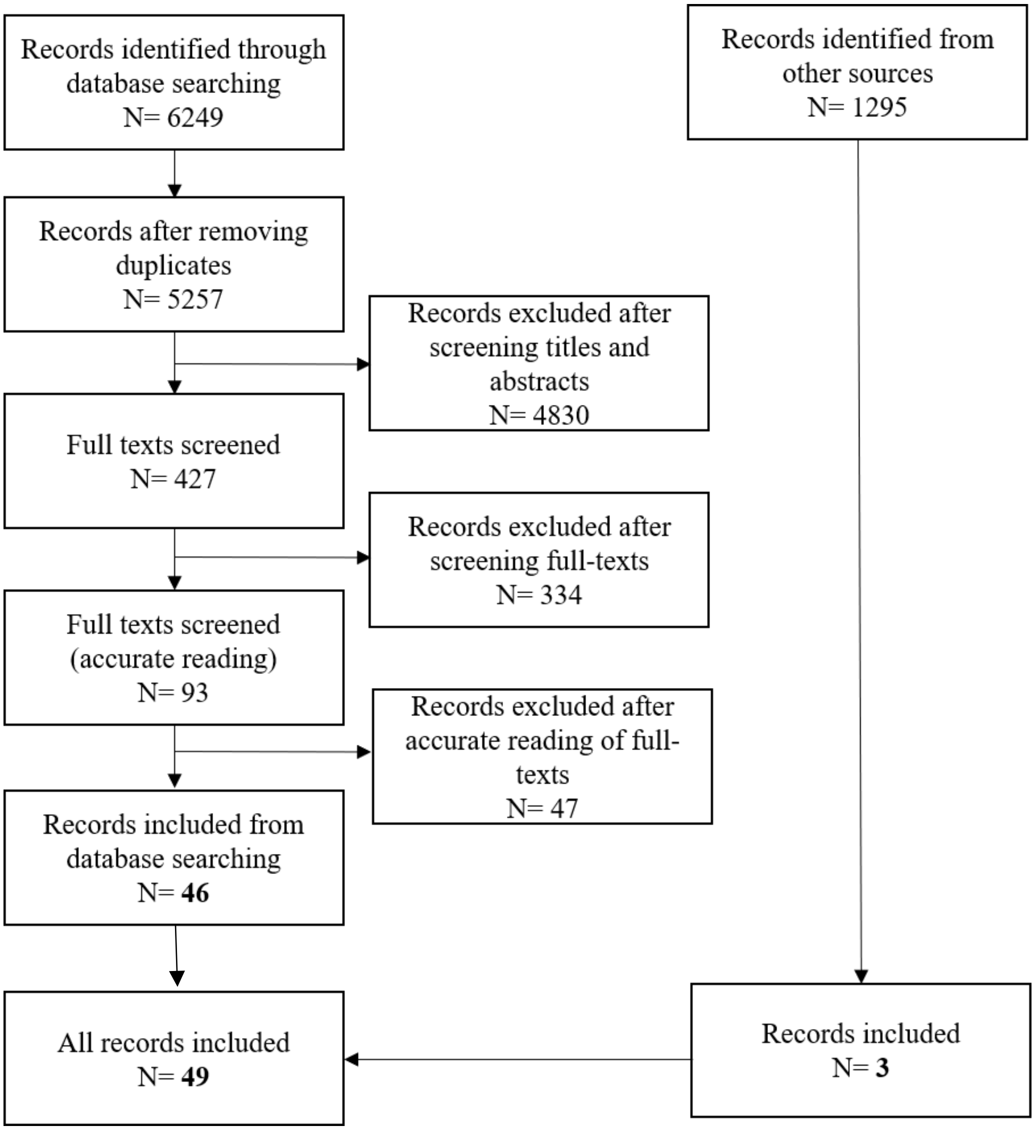

Figure 2.1. PRISMA flowchart – first search (February 2018 - March 2018).

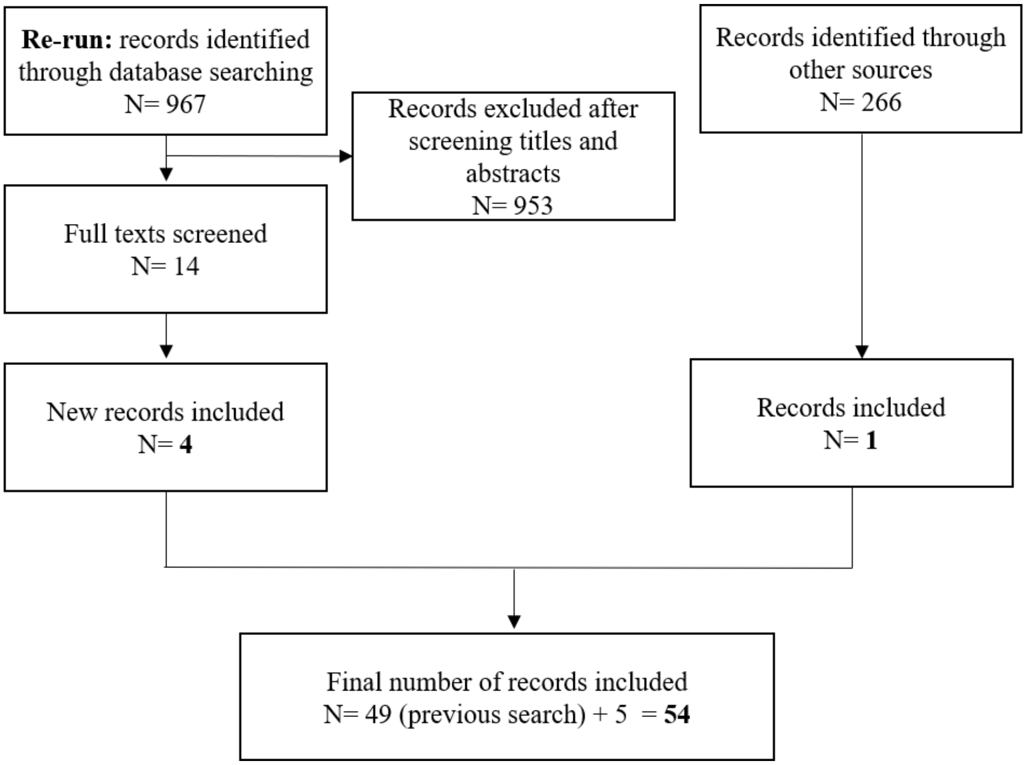

Figure 2.2. PRISMA flowchart – search update (September 2019).

Eventually, I included 54 records in my review. This number comprises 49 studies included after the first search, and five more studies included after the search update. These were 46 qualitative studies, six mixed-methods studies, and two qualitative literature reviews (of which one was systematic). The studies presenting primary data brought together the views of 1882 adults with long-term conditions, plus an ethnographic observational study in which the number of participants was not reported. Most of the studies (23) were about a variety of chronic conditions, followed by chronic pain (9), mental illness (5), cancer (4), diabetes (3), stroke and/or brain injury (3), degenerative disorders (3), heart failure (2), chronic kidney disease (1), and frailty (1).

2.3 Reading the studies

I read all the studies twice in order to familiarise with them. The first time I read the studies to familiarise with them was during the full-text screening phase, whereas the second time was during the data extraction and quality appraisal phase. The second time, I also noted down ideas to explore further during analysis, and extracted data from the documents by writing down the main characteristics of each study on a data extraction form that I developed previously. I extracted the studies' characteristics (i.e., title, year, authors, country, setting, and methodology), the participants' demographics, quotes, authors' interpretations, and any research, policy or practice implications. The second reviewer, Sophie Pask, also extracted data independently. There were no inconsistencies between our data extraction forms. I used the data extraction forms for quality appraisal purposes, and to determine how the studies were related.

2.4 Quality appraisal

Quality appraisal was carried out during the data extraction phase by me and the second reviewer, Sophie Pask, independently. I decided to employ the Joanna Briggs Institute (JBI) critical appraisal checklist for qualitative research, as I considered its focus on congruence and emphasis on the participants' voices compatible with the principles of meta-ethnography (Hannes *et al*., 2010). Two literature reviews were also included in the study, and I appraised them using the JBI critical appraisal checklist for systematic reviews.

Six mixed-methods studies were included in the review. In consideration of the substantial qualitative component in these studies, I used the JBI Critical Appraisal Checklist for qualitative research to assess the qualitative methods and findings of the studies. I decided to do this for the sake of consistency, so that all qualitative findings could be appraised according to the same criteria across the systematic review dataset, and because the outcomes of quality appraisal would not affect the outcome of the synthesis, as the studies' contribution would not be weighed based on their quality score.

Actually, although the need for distinguishing good quality studies from poor quality studies is agreed upon by most approaches to qualitative evidence synthesis (Garside, 2014), Noblit and Hare (1988) suggested that the exclusion of studies based on methodological quality is not advisable in meta-ethnography, arguing that what matters the most for meta-ethnography is conceptual richness. However, Campbell and colleagues (2003) used critical appraisal in their meta-ethnography as a way to quickly eliminate inappropriate papers. Therefore, I decided to contemplate the possibility of exclusion only if the primary study's methodology was deemed incompatible with its aim(s). Otherwise, studies were not excluded or weighed based on their quality, as my priority was that of capturing a wide range of people's experiences and voices. Results of quality appraisal have been reported in Appendix C (page 247). Differences in scores were often due to incomplete or poor reporting (e.g., "unclear" answers on the JBI checklist).

2.5 Determining how the studies are related

Noblit and Hare (1988) suggest determining how the studies are related before synthesising them. Since I was working with 49 records (54 after the search update), I followed Atkin's *et al*. (2008) approach and drew on the information extracted during the previous phase ("Reading the studies", section 2.3). Therefore, I used the data extraction forms for easier access to the main aspects of each study. I found that the studies were quite heterogeneous when it came to their specific characteristics (i.e., populations, health conditions, and concepts investigated among others), except for their settings. Therefore, I decided to relate the studies based on their setting, and divided them into three groups: those conducted in primary care settings (18 studies), those conducted in secondary care settings (19 studies), and those conducted in mixed or hybrid settings (17 studies).

2.6 Translating studies into one another

Reciprocal and refutational translation is the stage of meta-ethnography in which the studies' key concepts are translated into each other (reciprocal translation), while any differences and inconsistencies between the them are noted down and explored (refutational translation) (Sattar *et al*., 2021). In this section, as well as in sections 2.7 and 2.8, I describe in detail the analytical process of reciprocal and refutational translation that eventually led me to the development of four main themes: (1) the perception of the healthcare system as a battlefield, (2) the perception of the healthcare system as a maze, (3) processes of patient enablement, and (4) the patients' accounts of personhood. I present the findings of this synthesis using verbatim quotes from the original studies, though I occasionally provided any clarifications in square parentheses when appropriate.

I started carrying out the reciprocal and refutational translation after transferring the electronic versions (pdf) of each record to NVivo 12 (QSR International, Melbourne, Australia). I decided to use NVivo as Atkins *et al*. (2008) suggest resorting to computer-assisted coding to facilitate meta-ethnography's analytical process with relatively large numbers of studies, which was the case for my review.

As described in section 2.5, I divided the studies in three groups (primary care studies, secondary care studies, and mixed/hybrid settings studies). I analysed each group separately, starting from the oldest paper in each group. Here, I present examples of how I conducted the analysis using two consecutive studies that were carried out in secondary care settings: the study by Cott (2004), entitled "client-centred rehabilitation: client perspectives", and the study by Harding *et al*. (2005), entitled ""It Struck Me That They Didn't Understand Pain": The Specialist Pain Clinic Experience of Patients with Chronic Musculoskeletal Pain". I started by coding Cott's paper, as it was the oldest study in the 'secondary care settings' group. As meta-ethnography is designed to take into account the unique context of each study (France *et al*., 2019), I read the introduction and methods section and noted down anything that I considered relevant as study context (an example is the note "Cott's study is based on symbolic interactionism"). Then, I proceeded to code the results and discussion sections on NVivo. At this stage, I mainly used descriptive codes, to help me identify key concepts in each paper and thus facilitate reciprocal and refutational translation. After coding Cott's paper, I ended up with a raw list of codes (see table 2.2).

Table 2.2 – Raw codes in Cott's paper

- Expectations of patient's passivity
- Involvement in treatment decisions
- Facilitators to patient involvement
- Patient as a unique person
- Feeling labelled
- Distrust in patient's skills
- Barriers to decision-making
- Patient's expectations
- Dynamicity of preferences
- Emotional support
- The expert role
- Clinician's positive behaviour
- Beyond the clinical sphere
- Transition and discontinuity issues
- Feeling dehumanised
- Barriers to information
- Healthcare needs upon discharge
- Continuity
- Challenges for healthcare professionals

Afterwards, I coded Harding's paper following the same process. Since the papers were in the same library on NVivo, I could still access Cott's coding index when assigning a (new) code to a segment of text in Harding's paper. This helped me identify similar concepts (reciprocal translation) hence some codes that I used for Cott's paper were used to code parts of Harding's paper too. For example, I coded the following extract from Cott's paper as "Beyond the clinical sphere".

> "Many of the skills that participants identified as lacking went beyond physical functional tasks to include learning to manage interpersonal

> relationships and deal with the emotional challenges associated with having a chronic condition.” (Cott, 2004, p. 1416)

Upon reading Harding’s paper, I coded the following piece of text as “Beyond the clinical sphere” as well:

> “Failure to address patients’ sense of spoiled identity and loss of trust in the medical profession may be important factors that are not fully addressed in our current approach to treating chronic pain.” (Harding *et al*., 2005, p. 696)

Noblit and Hare (1988, p. 40) wrote that reciprocal translation “requires the assumption that the studies can be “added” together”. In this case, I thought that the concepts expressed in these two segments added something to each other, as both gave examples of an approach that goes beyond the clinical sphere. For example, the authors indicate the desirability of clinicians going beyond “physical functional tasks” in Cott’s paper, and beyond the “current approach to treating chronic pain” in Harding’s and colleagues’ paper. What they add to each other, is the need to address other aspects of the patients’ lives (i.e., the personal aspect in Harding’s study, and the relational and emotional aspects in Cott’s study). This process also highlights the importance of the study’s context during translation in meta-ethnography. For example, I could interpret Harding’s “current approach to treating chronic pain” as related to the clinical aspects of care because they later wrote that “developing new ways to tackle these important issues will move chronic pain management forward from *simply addressing pain and disability* [my emphasis] to being able to address the full spectrum of issues that impact patients’ lives and self image.” (Harding *et al*., 2005, p. 696).

Other codes were not necessarily translatable into each other, yet I thought they belonged to the same category. For example, I started identifying different healthcare needs throughout the papers (e.g., emotional support and involvement in Cott’s paper, and being listened to and legitimacy in Cott’s paper), and decided to put them under the umbrella of “healthcare needs”.

After working on Cott's and Harding's studies, I started coding the following (third) study in chronological order, and compared its coding summary with the previous one (the result of Cott's and Harding's reciprocal translation and merging process), engaging in the same process as before, and eventually ending up with a new version of the coding summary.

Sometimes, during this process, I would find contradicting information. This was a relatively rare instance, as the participants' positive and negative experiences tended to have several aspects in common. However, I noticed that what changed was the participants' response to their experiences. For example, in the context of disagreement between patients and healthcare staff, I coded some data as "Patient takes the initiative" or "Patient as the expert" and others as "Patient's resignation" and "Doctor as the expert". As these contradicted each other, I engaged in refutational analysis by going back to the primary studies to explore reasons behind these differences. I provide examples of what I found through this refutational analysis in section 2.7.1 (page 41), "the perception of the healthcare system as a battlefield".

After carrying out the reciprocal and refutational translation with the last paper of each group (i.e., primary care, secondary care, and hybrid/mixed settings groups), I ended up with three different thematic indexes. The indexes had both similarities and differences, though, in general, studies conducted in primary care settings had more codes about the clinician-patient relationship, whereas studies conducted in secondary care settings had more codes about service efficiency and coordination. On the other hand, codes about the patient as a person or about the provision of information and communication were common across all groups. At this stage, I started working towards developing a line-of-argument synthesis.

2.7 Moving from reciprocal and refutational translation to a line-of-argument synthesis: developing themes

I transferred the records from all the three groups on a single library on NVivo. This initially resulted in a library with 49 records (with five more records added at a later stage after the search update), which allowed me to examine the dataset as a whole. Since I had a relatively large number of records, I decided to identify the main categories across the entire dataset, in order to understand how pieces of data from different study groups were related, before starting to compare and explain them (thus engaging in a more interpretative work). By merging similar (or identical) codes, I identified seven broad categories:

1) Barriers to positive healthcare experiences
2) Facilitators to positive healthcare experiences
3) Healthcare needs
4) Clinician-patient relationship
5) Biomedical vs biopsychosocial perspectives
6) Perspectives on expertise
7) The person behind the patient

Then, I shared the codebook with my supervisors Joanne Reeve and Julie Seymour, so that they could check for coding consistency and appropriateness. The codebook included the categories and codes along with the corresponding quotes. At this point, the main challenge lay in the breadth of information generated after the initial stage of analysis. Therefore, I went back to my study aim (i.e., to develop a critical understanding of the essential aspects of person-centred care from the perspective of people with long-term conditions), and refined the code list. For example, I excluded any codes that were not rich enough or relevant to the research aim (e.g., codes related to challenges for healthcare professionals, as they mainly reflected the professionals' perspective).

Once the studies were pooled together, I engaged in a new process of reciprocal and refutational translation by comparing themes and codes across different study groups. This two-level translation process was necessary in the case of my review, because translation in meta-ethnography should be more idiomatic rather than literal (Campbell *et al.*, 2012), but the high number of studies included in my review did not allow me to work at a deeper interpretative level during the first coding round.

For example, at this stage, by looking at the codes and quotes in the category "barriers to positive healthcare experiences" across different study groups, I noticed some tension in several accounts, but I could not explain such tension until I found that, in one of the studies, the healthcare system was perceived as a "battlefield".

> "By using war metaphors like "fight" and "battle", they [the participants] describe their engagement with public healthcare services as being caught in a battlefield. The battle is a power struggle over one main question: who is to decide?" (Lian and Robson, 2017, p. 10)

As I checked other studies with similar examples of such tension, I started identifying war metaphors/language elsewhere too (terms such as "fight" and "battle", but also "struggle", "army", "hostile", and so forth). A word query on NVivo helped me find even more instances of this language. I contextualised all those instances, to make sure they referred to healthcare experiences (e.g., they were not metaphors about fighting against the illness). However, whereas Lian and Robson in the previous quote associated the "battlefield" with decision-making issues, the instances of conflict that I found in other studies were also about other aspects of the patients' healthcare experiences, such as access to resources and patients' feelings of vulnerability. This is how I developed the first theme, "the perception of the healthcare system as a battlefield". I describe this theme more in detail in the next section.

2.7.1 Theme 1: The perception of the healthcare system as a battlefield

I identified the perception of the healthcare system as a battlefield through the participants' feelings of anger and fear to speak up when something was wrong, the occasional perception of health professionals' aggressiveness, and the appearance of war metaphors and language across the dataset. For example, one participant used the word "army" to refer to a group of medical students accompanying her care team during clinical visits (Benham-Hutchins *et al.*, 2017).

These data indicated that there was a perceived power struggle, for example when patients said they were afraid the doctor would punish them if they disagreed with them (Lian and Robson, 2017). In other instances, they believed that they had to fight to defy paternalistic attitudes (Morris *et al*., 2018), and to access medical resources (Ho *et al*., 2017). Such perception led some patients to believe that clinicians were unwilling to share information with them (Cott, 2004), or would actively get in their way to prevent them from getting information (Wright *et al*., 2016). Other participants were afraid to be a "bother" (Bayliss *et al*., 2008, p. 290) and thus refrained from asking for help or communicate with the staff.

> "I sensed that I was troublesome to [the nurse] and she didn't like me . . . this made me upset. I dare not communicate and talk anymore with her in the future" (Chan *et al*., 2018, p. 9)

Contrasts were present also when role expectations differed between patients and clinicians. Whereas some patients thought that clinicians were "the experts" (Cooper *et al*., 2008; Protheroe *et al*., 2013), and should decide for them (Teh *et al*., 2009), in other instances they believed that nobody could understand their illness better than themselves, and wanted to be viewed as proactive patients with their own skills and expertise (Jowsey *et al*., 2011; Raven *et al*., 2012; Duthie *et al*., 2017; Lian and Robson, 2017). I investigated reasons behind such different attitudes through refutational translation. For example, patients tended to think that clinicians were the experts because they thought clinicians trained for years or "have the degrees" (Teh *et al*., 2009, p. 524; Protheroe *et al*., 2013). Patients accepted most of the clinicians' decisions, especially when such decisions were communicated and explained clearly (Cooper *et al*., 2008). On the other hand, other patients thought of themselves as experts because they knew their body (Duthie *et al*., 2017), as well as the social, mental, and physical consequences of their symptoms, which they said clinicians did not know (Lian and Robson, 2017).

When the goals of healthcare staff and patients differed, patients either accepted the situation (Nakrem *et al*., 2011; Toles *et al*., 2012), did not adhere to the treatment (or made their own medical decisions) (Cooper *et al*., 2008; Teh *et al*., 2009), looked for a second opinion (Östman *et al*., 2015), or stopped using healthcare services altogether (Sheridan *et al*., 2015). In other instances, patients would take the initiative differently, for example by trying to educate their physicians about their illness (Egeli *et al*., 2008; Bergman *et al*., 2013) or demanding to see "someone higher up" (Teh *et al*., 2009, p. 524). Still, for some authors, even seemingly passive behaviours like non-adherence or the adoption of unhealthy lifestyles in spite of the doctors' advice could be seen as "powerful statements of self-determination" (Sheridan *et al*., 2015, p. 40).

Along with the power struggle and battlefield metaphors found across the dataset, the participants in the studies also showed that they had difficulties accessing and navigating healthcare services. From these instances, I developed the theme of "the perception of the healthcare system as a maze", which I describe in the next section.

2.7.2 Theme 2: The perception of the healthcare system as a maze

The process leading to the development of the theme "the perception of the healthcare system as a maze" resembled the process described for the previous theme (the perception of the healthcare system as a battlefield). I initially identified the maze metaphor in Jowsey's and colleagues' (2011) study, in which the word 'maze' was used to refer to the health system. From there, I realised there were numerous instances in which the participants reported difficulties 'navigating' or 'accessing' the health system (Cabassa *et al*., 2014), or feeling 'lost' in the healthcare and decision-making process (Wright *et al*., 2016).

For example, several participants in the reviewed studies had a hard time finding out which services were available, trying to access services and information, and coordinating the information collected across different settings. These people received care that did not meet their needs, such as information exchange and retrieval and identification of/access to health services. Even when the clinician was valued as an expert and a source of knowledge, organisational issues such as lack of time meant that patients were unable to find a way to get information from them (Zizzo *et al*., 2017).

In general, getting in touch with the health centre's staff was perceived to be challenging in primary care settings (Protheroe *et al*., 2013). In this context, the participants emphasised the importance of relational continuity (i.e., seeing the same clinician every time) as it contributed to feelings of security and consistency (Cocksedge *et al*., 2011; Nygren Zotterman *et al*., 2016). Flexible continuity, namely timely access to care, and the practice staff's ability to make and change appointments efficiently (Naithani *et al*., 2006) was also mentioned by the participants as a desirable aspect of care.

Patients also made recommendations to help them access and navigate healthcare services; examples are the presence of a care coordinator (Bayliss *et al*., 2008), availability of online and offline resources that people can access after discharge (Benham-Hutchins *et al*., 2017), and centralised information systems that could facilitate provider access to patient data (Dams-O'Connor *et al*., 2018).

Whereas the two themes described so far (the healthcare system as a battlefield and/or a maze) refer to negative healthcare experiences, positive experiences were also found in the dataset, leading me to the development of the theme "processes of patient enablement".

2.7.3 Theme 3: Processes of patient enablement

The theme "processes of patient enablement" was developed through the analysis of the positive experiences that were also present in the dataset. Through this process, I looked at categories such as "healthcare needs" and "facilitators to positive healthcare experiences", and realised that the absence of battlefield/ maze elements alone did not explain positive, and possibly person-centred healthcare experiences. What characterised such positive experiences was also the presence of active enablement processes, namely processes and actions that supported the patients' proactivity in the care of their own conditions. For example, access to tailored information was valued because it enabled patients to better understand the circumstances around their disease, and make informed choices. Information exchange usually took place when the patient was enabled to engage in such activity, for example when a good relationship with the doctor, and a favourable organisational culture (Hartley *et al*., 2011; Dams-O'Connor *et al*., 2018), allowed them to "ask and talk freely" (Abdulhadi *et al*., 2007, p. 4).

Such positive relationships were built on mutual respect, legitimisation of the patient's illness experience, friendliness, care, trust, empathy, emotional support, and openness. They were also characterised by the clinicians taking time to listen to what patients had to say, and patients being known or remembered by their doctors (Kuluski *et al*., 2013). Being known not only made patients feel valued as individuals, but also saved them the work of repeating their medical histories to healthcare professionals that did not know them, or that did not read their medical records (Brown *et al*., 2015). Furthermore, the participants believed that the opportunity to share their knowledge and experiences should be considered valuable from a clinical point of view. Patients' accounts also expressed a wish for clinicians to adopt more holistic, whole person approaches to their care (Egeli *et al*., 2008; Sav *et al*., 2013; Baudendistel *et al*., 2015; Lian and Robson, 2017).

It should be noted that a good relationship with the doctor, though valuable in itself, was often instrumental to taking action and knowledge-building. Therefore, the clinician's competence and ability to understand and address the complexity of the participants' illnesses, and to refer them to community or specialist services when applicable, was considered to be complementary to a good relationship.

> Simply being ''nice'', however, was not welcomed if ineffective: "All the doctors are very nice, but they don't take any notice…They don't do anything." (Clarke, *et al*., 2014, p. 5)

In turn, knowledge-building was also considered to improve the patient-clinician relationship (Fu *et al*., 2018). Still, some patients lacked knowledge about their own condition, hence being prevented from engaging in effective decision-making and self-management (Murphy *et al*., 2015). For example, language issues (e.g., not speaking the local language fluently) could represent a barrier to patient enablement (Jowsey *et al*., 2011; Cabassa *et al*., 2014), as well as low socio-economic status and low levels of health literacy (Protheroe *et al*., 2013; Murphy *et al*., 2015).

Finally, the last theme identified during the analysis was "the patients' accounts of personhood", which stemmed from the analysis of the participants' reactions to both positive and negative experiences of healthcare, as described in the next section.

2.7.4 Theme 4: The patients' accounts of personhood

The aim of this meta-ethnography was to develop a critical understanding of the essential aspects of person-centred care from the perspective of people with long-term conditions by exploring their healthcare experiences. Still, during the analysis, I noticed that certain healthcare experiences ended up going beyond the healthcare sphere, and affected the participants on a personal level. By identifying accounts of patients feeling dehumanised, worthless, neglected, and invisible, I found instances of healthcare experiences that affected people's sense of personhood and identity. With these new lenses, I started identifying even more examples from several accounts across all three groups of studies. An example of perceived dehumanisation found in the data was the following:

> "Discussions about my situation and my care were had while I was sitting in the room with [the care team and the medical students], only they did not actively acknowledge my presence, so I felt like an animal at the zoo." (Benham-Hutchins, *et al*., 2017, p. 6)

Once identified, such examples led me to develop the fourth and last theme, "the patients' accounts of personhood". As regards negative experiences, the participants' perception of the healthcare system as a battlefield and/or a maze brought about feelings of frustration, humiliation, and isolation, and led some of them to lose faith in the system or in their doctor (Harding *et al*., 2005; Protheroe *et al*., 2013; Svanström *et al*., 2013). In this context, some patients complained about not being seen as "persons". However, the importance of personhood was also highlighted in a positive way, when some participants admitted that being seen as a person allowed them to “show the true reflection of self”, giving them more confidence in the clinical environment (Hartley *et al*., 2011, p. 15).

Nonetheless, some patients also reported feeling labelled as hypochondriacs or drug seekers (Upshur *et al*., 2010), or complained that their reported physical symptoms (e.g., pain and fatigue) were attributed to mental disorders (Cabassa *et al*., 2014), laziness, and stereotyping (Lian and Robson, 2017). In such situations, some of them mentioned feeling dehumanised (Cabassa *et al*., 2014). Examples of this were numerous, as the participants said that the healthcare staff made them feel like numbers (Bergman *et al*., 2013; Winsor *et al*., 2013), objects (e.g., a rock, a piece of the furniture) (Cott, 2004; Raven *et al*., 2012; Sheridan *et al*., 2015), or animals (Benham-Hutchins *et al*., 2017; Harrison and Frampton, 2017).

2.8 Line of argument synthesis: The essential aspects of person-centred care

After developing the four themes described in the previous section, I engaged in meta-ethnography’s line of argument synthesis. Noblit and Hare (1988) did not provide specific guidelines on how to conduct the line-of-argument synthesis, and defined it as a phase in which the researcher reaches an overarching interpretation of the findings, which goes beyond the single contribution of each study. Through the line-of-argument process, the synthesis therefore becomes more than the sum of its parts (Gough *et al*., 2017). I engaged in this synthesis by looking at themes and sub-themes, and drawing relationships between them. I started by putting themes and sub-themes on a table (see table 2.3).

Table 2.3. List of themes and sub-themes.

1. The battlefield	**2. The maze**	**3. Enablement**	**4. Personhood**
- Perceived power imbalance - Perceived vulnerability - Feelings of fear - Feelings of anger - Perception of fighting a battle - Clinician's negative attitudes - Clinician's disinterest	- Difficulties identifying services - Difficulties accessing services - Difficulties getting information - Difficulties understanding information - Navigating the system - Access to patient data	- Tailored information - Clear communication - Flexible communication - Positive relationship - Listening to the patient - Knowledgeable and competent healthcare professional - Involvement - Adoption of a biopsychosocial perspective	- Dehumanisation - Impact on patient's self-worth - Patient's unique characteristics - Feelings of humiliation - Feelings of being neglected - Patient vs Person

Then, I transferred all the sub-themes and their respective quotes on a new document, to start looking for potential relationships between different themes and sub-themes. This process was grounded in the data, as I always went back to the original studies to check whether a relationship between different sub-themes could be explained in the context of each study. For example, as my goal was that of understanding person-centred care from the perspectives of people with long-term conditions, I started looking at enabling processes' (theme 3) sub-themes and their respective quotes. I realised that there could be relationship the sub-theme "positive relationship" (theme 3, enablement) and the participants' personhood (theme 4), like in the following example:

> "They treat you as a normal person… I'm not regarded as a person with a disability. …… I'm not judged in anyway here either. It's like I said a comfortable environment." (Hartley *et al.*, 2011, p. 1027)

In this case, my interpretation was that being treated in a non-judgmental way ("positive relationship" sub-theme) made the environment comfortable, but also made the patient feel like his or her personhood was being valued instead of reduced to his or her disability. As I found other instances of how similar healthcare experiences improved as a result of a positive relationship with the staff, I identified "relational aspects of care" as part of what is needed to achieve person-centred care from the participants' perspectives.

By looking for further instances, I eventually found other relational aspects that improved people's healthcare experiences, and wrote them down in a table (table 2.4).

Table 2.4. Relational aspects of care that affected the participants' healthcare experiences.

Relational aspects of care
Respect
Trust
Care
Emotional support
Reassurance

As I proceeded with my work of looking for relationships between different themes, I identified other aspects of the participants' healthcare experiences that were person-centred, yet were not relational in nature, but organisational instead. For instance, organisational aspects of care were identified in quotes cutting across both the maze and enablement themes, as in the following example:

> A barrier that was repeatedly cited by respondents from the lower SES [socioeconomic status] group was of the increasingly complicated appointment systems in place in primary care. Many respondents reported that they relied on chance and the system, some felt frustrated by this system but felt that they could do nothing about it. The respondents from the higher SES group, however, consistently reported being able to navigate the system in order to see their preferred health-care professional. (Protheroe *et al*., 2013p. 1052)

In the previous quote, the comparison between a lower SES and a higher SES group indicated that certain organisational aspects of care, such as the appointment system, were too complicated for some people, yet other people were “able” to “navigate” them. This was an indication that people can be enabled to engage in an optimal way with the organisational aspects of care, for example through a simplified appointment system. I thus identified other examples of organisational aspects of care, and noticed how they could relate to both positive and negative healthcare experiences. As I did for the relational aspects of care described previously, I noted down organisational aspects of care that affected the participants’ healthcare experiences (see table 2.5).

Table 2.5 Organisational aspects of care that affected the participants' healthcare experiences.

Organisational aspects of care
Timely care
Integrated care
Continuity
Flexibility
Coordination
Accessible environment
Organisational culture

Finally, I realised that several sub-themes (e.g., 'tailored information') across the four themes were not directly attributable to organisational or relational aspects of care, but referred to activities such as knowledge and information exchange. As for the previous examples, I looked for relationships between such sub-themes and others, and found that knowledge building and information exchange were another aspect of care that could affect (either positively or negatively) the participants' healthcare experiences. For example, they related with the battlefield theme when their lack was perceived as intentional.

> They don't want you to see anything and they don't want you to know anything. If you ask a question, oh well, 'that's none of your business' or 'oh we don't have time for this' (Wright *et al.*, 2016, p. 5)

In the previous case, the participant in Wright's and colleagues' (2016) study uses a hostile language ("that's none of your business") to describe how the staff reacted to his request for information. Similarly, information provision and good and clear communication also created enabling healthcare experiences.

> It was only when primary health-care clinicians appeared to 'extend their reach' into the territory of engagement by paying attention to what patients said they wanted and discussed their real needs that patients felt able to

> participate. In these situations, clinicians were enablers and created the conditions necessary to empower patients (Sheridan *et al*., 2015, p. 39)

In the previous example, I interpreted "*paying attention* [my emphasis] to what patients had to say" as an epistemic effort, with enabling effects ("patients felt able to participate", "clinicians were enablers") described by the authors. This way, I identified several epistemic aspects of care (table 2.6). I decided to use the term epistemic because words like "information" or "knowledge" can have different meanings, and I wanted to use a term that could encompass them both, as well as other related or relevant concepts, such as data and wisdom (Ackoff, 1989).

Table 2.6. Epistemic aspects of care.

Epistemic aspects of care
Availability of information
Exchange of information
Healthcare professionals' competence
Healthcare professionals' understanding
Treatment and symptom management

At this stage, there were still some aspects of care among the sub-themes that needed further definition. I reflected on this when I looked at the "Listening to the patient" sub-theme, and realised that I could not determine whether it belonged to the relational or epistemic aspects of care. Initially, I believed it belonged to the relational aspects of care, as shown by the following examples:

> Listening is the big thing that makes a difference. There are limited treatments for FM [fibromyalgia], so giving the patient a voice helps emotionally (Egeli *et al*., 2008, p. 366)

> Another important aspect of the patient-provider relationship was the sense of being heard. […] "She listens to me. She's the only one that does... I trust her with everything... She... doesn't cut me off... she'll... listen to

> anything I have to tell her, and then that’s it... she does not cut me off.” (Teh *et al.*, 2009, p. 525)

In the previous examples, being listened to had relational implications, as it helped emotionally or led the patient to trust the professional. Still, as I kept looking for instances of listening across the dataset, I noticed that it also had epistemic implications:

> “It is I who know my body and what happens when I am overstrained, socially, mentally and physically [. . .] I can’t expect my GP to have this knowledge, but I can expect my GP to listen to what I have to say.” (Lian and Robson, 2017, p. 4)

I noticed that several participants in the reviewed studies did not want to be listened only because it made them feel cared for and valued, but also because they believed they had important information to contribute to the clinical encounter. I concluded that “listening to the patient” had a boundary-spanning nature, laying at the interface between the relational and epistemic aspects of care because, according to the data, it was contributing to both. In the same way, I identified further aspects of care laying at the interface between the organisational and the relational aspects, and others laying between the organisational and epistemic aspects. This indicates that the boundaries between these aspects of person-centred care are not clearly defined, and that all the elements interact to contribute to the whole, with each aspect being necessary, but not sufficient, to the achievement of person-centred care.

In consideration of the nature of this review, I could not infer whether any specific aspects of care were more or less important than others. Therefore, I put the three main aspects of care (organisational, relational, and epistemic) and their interfaces on the same level. In order to provide a non-hierarchical visual representation of this, I drew a triangle-shaped picture (figure 2.3).

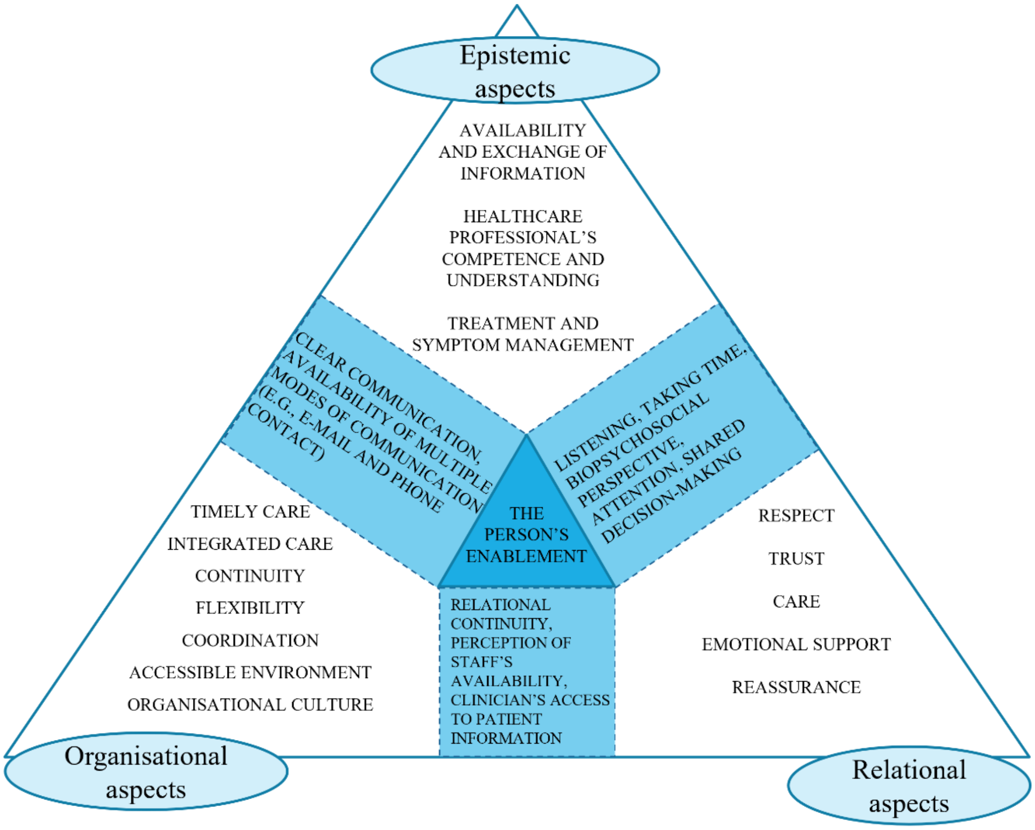

Figure 2.3. Diagram presenting the essential aspects of person-centred healthcare described by the experiences of people with long-term conditions.

At the centre of this diagram lies the person's enablement, as the patient/person inevitably interacts with all these aspects when attending healthcare services, but in some cases also needs to be enabled to engage with them proactively and successfully. It is important to specify that "enabling" is not a synonym of "helping" but refers to the achievement of a balance between offering help and respecting the patient's independence, which requires a cognitive effort, as well as effective communication and sensitivity on the side of the practitioner (Laitila *et al.*, 2018), who has to adopt a flexible consultation style between (and sometimes within) consultations (Hancock *et al.*, 2012). Paternalism, under the guise of "too much help", was often contrasted by patients, and ended up contributing to the "battlefield" theme rather than to the "enablement" theme.

2.9 Expressing the synthesis

Expressing the synthesis is the final step of meta-ethnography. As can be seen throughout this chapter, I described the methodological aspects of the process and expressed the synthesis narratively, with the original quotes and their descriptions written down in narrative form. Finally, I developed a visual representation of the synthesis by drawing a diagram that included the aspects of person-centred described by people's healthcare experiences, which I have shown in the previous section (§ 2.8, page 54).

2.10 Search update

I updated the search in September 2019, approximately one year and a half after the original search, before submitting the systematic review manuscript to a journal. After the update, I included five more papers in the pool of studies. These were all qualitative studies, of which four belonged to the secondary care studies group, and one to the primary care studies group.

For the sake of consistency, I still coded such papers in the same way as described in section 2.6 (page 35). As this was a search update, the identified papers were more recent than the ones that had already been included in the review, hence it was possible to keep the chronological order of the analysis. However, among the five studies, one was identified through reference list checking, and was published in 2012, hence being older than some of the papers I had analysed previously. Still, it was neither feasible nor necessary to go back and repeat the reciprocal and refutational translation for all the studies published after 2012 in the group, hence I coded such study without following the chronological order. At the end of the process, I compared the studies' final coding indexes with the final coding indexes of their respective group. However, the new indexes did not alter the final coding index of any group. Along the same lines, the codes and themes identified in the new studies fell under the categories and the final four themes identified previously (i.e., battlefield, maze, enablement, and personhood), so there was no need to change or add any themes to the final list. Eventually, the addition of the new studies mainly contributed to the quality of the final reflection and discussion about the meta-ethnography's findings, by providing additional perspectives, but they ultimately reinforced or confirmed the findings of the line-of argument synthesis.

2.11 Strengths and limitations of this meta-ethnography

A strength of this review is that screening, data extraction, and quality appraisal were done independently by two reviewers (Sophie Pask and I) on all the records. A limitation is that types of care such as telecare and home care were excluded from the review. However, this was done to keep the review as focused as possible, as there was a large number of studies about telecare and homecare, which could warrant a separate review.

Another strength is that I have updated the search prior to submission. The update resulted in five more papers being added to the systematic review. Still, although these papers contributed to the quality of the reflection by offering further insights in the interpretation of the studies, no new themes were developed (or changed) after the analysis of the new records, hence the addition of the extra records did not affect the findings significantly.

Also, this meta-ethnography allowed for the synthesis of the views of a large number of people, which is a strength as qualitative studies rarely involve high numbers of participants. However, along these lines, a limitation is that fifty-four studies might challenge the interpretative nature of a meta-ethnographic approach (Campbell *et al*., 2012). Yet, the use of meta-ethnography with a relatively large number of studies has been documented before (Atkins *et al*., 2008; Toye *et al*., 2013). I addressed this challenge by considering the guidelines reported on methodological studies on the use of meta-ethnography with large numbers of studies (France *et al*., 2019), using a computer assisted analysis software to facilitate the synthesis, and dividing the studies in three groups so that each group could be analysed in-depth.

Finally, a well acknowledged challenge of synthesising different studies in meta-ethnography lies in the epistemological differences between studies. Such challenges in qualitative evidence synthesis have long been object of debate (Bondas and Hall, 2007). Originally, meta-ethnography was devised as a way to synthesise ethnographic findings, which tend to include thick descriptions and interpretations, but studies about healthcare experiences as those included in this synthesis have a more applied nature (Atkins *et al.*, 2008). Whereas meta-ethnography has been found to be suitable to the synthesis of both qualitative and mixed-methods studies (Da Silva *et al.*, 2013), epistemological assumptions tend to vary not only between qualitative and mixed-methods studies, but also between qualitative studies themselves. Therefore, I decided to undertake the analysis of all qualitative data through interpretative lenses, by engaging in the hermeneutic circle of going back and forth between parts (i.e., pieces of data) and the whole (i.e., the dataset) (Rennie, 2012), using metaphors and imageries, and so understand the meaning of the participants' experiences to produce a thick description of themes and interpretations (Bhattacherjee, 2012). I did this because meta-ethnography originated from the interpretive paradigm, and so did most methods of qualitative research (Campbell *et al.*, 2012), while mixed-methods studies allow for flexibility of research paradigms (McChesney and Aldridge, 2019).

Concluding remarks

I carried out this meta-ethnography with the aim to develop a critical understanding of the essential aspects of person-centred care from the perspective of people with long-term conditions. This meta-ethnography identified three essential elements of person-centred care: epistemic, relational, and organisational. These aspects all interact across their interfaces, indicating that they all work together towards the achievement of person-centred care.

The previously recognised importance of the doctor-patient relationship was highlighted by this review, which also emphasised that the achievement of a good relationship between the patient and the clinician needs to be enabled by organisational aspects of care, such as care coordination and integration, flexibility, and continuity. This means that the doctor alone cannot achieve person-centred care, and they also need to be enabled to engage in person-centred clinical encounters by the healthcare system organisational setup.

The epistemic aspect is a new element not previously well described from a patient perspective in the literature on person-centred care, and so became the area I would focus on in the next part of my doctoral research. Throughout this chapter, instances of positive and negative healthcare experiences referred not only to the relationship with the staff, but also to how the staff decided to share information with patients. For example, the person interviewed in the study by Benham-Hutchins and colleagues (2017) (section § 2.7.4, page 46) complained about feeling like an "animal at the zoo", hence being excluded from a moment of learning about her own clinical situation, and that was taking place right in front of her. Only medical students and the care team were learning and talking about the patient, who lost her sense of personhood as a result (by feeling like an animal instead). This is an example of the epistemic injustice as discussed in Chapter 1.

Therefore, this review offered insights into how epistemic injustice occurs. In the case described in the previous paragraph, the data revealed an example of "participant injustice", a form of epistemic injustice that Hookway (2010) describes as hindering the capacity of a potential participant (i.e., the patient in Benham-Hutchin's study) to make a contribution to a collaborative inquiry (i.e., what was happening among the care team and the medical students). Instances of testimonial injustice (see Chapter 1, page 21) were also present in the qualitative evidence synthesis' dataset, and included examples of patients' reports on their symptoms being dismissed because they were attributed to mental disorders (Cabassa *et al*., 2014), laziness and stereotypes (Lian and Robson, 2017). This meta-ethnography identified examples of epistemic injustice evident in both epistemic aspects of care (e.g., information sharing), and relational aspects of care (e.g., perceived hostility of the healthcare staff). Therefore, the focus of the next part of my thesis is on the knowledge work of people with long-term conditions in the context of clinical consultations in which patient and doctor interact.

To conclude, this meta-ethnography found that people with long-term conditions describe a person-centred healthcare system as one that values and respect their personhood, and enables them to build knowledge together with the clinician in order to manage their illness in a safe, caring, and accessible environment. It showed that different forms of epistemic injustice do occur in healthcare settings, and in various ways, prompting the question as to whether the decades of debates around person-centred care and methods are reflected by people’s actual healthcare experiences (Lian and Robson, 2017).

After this review identified examples of epistemic injustice in healthcare settings, I decided to focus on the knowledge work of people with long-term conditions in the context of their healthcare experiences, to explore how changes to our approaches to patient knowledge work can strengthen person-centred care. In order to describe such knowledge work and experiences in depth, I decided to adopt a qualitative methodology and to carry out individual interviews and focus groups with adults with long-term conditions. In the next chapter, I describe the multi-method qualitative methodology that I designed and applied to the second part of my doctoral research.

Chapter 3 – Research Methodology: A qualitative, multi-method approach

As described in Chapter 2, the initial part of my doctoral research consisted in a meta-ethnography of published literature on the healthcare experiences of people with long-term conditions. This identified three aspects that describe person-centred care from a patient perspective: epistemic, relational, and organisational. As the review identified instances of epistemic injustice in the interaction between patient and doctor, such as in moments of information and knowledge exchange, I decided to focus on the knowledge work of people with long-term conditions and its role during clinical consultations for the next stage of my research.

Furthermore, in Chapter 2, I addressed my first aim ("to develop a critical understanding of the essential aspects of person-centred care from the perspective of people with long-term conditions") and described my methodological approach to meta-ethnography. In this chapter, I describe the methodology for achieving the second and third aims of my study, namely (2) to systemically describe the knowledge work of people with long-term conditions in the context of their healthcare experiences; and (3) to critically consider whether changes in approaches to understanding and supporting patient knowledge work can foster the enhancement of person-centred care. I outline my background as a student and a researcher, the philosophical underpinnings of my work in this second part of my research, along with my choice of methodological approaches, and the details of the methods applied to achieve the study aims described in Chapter 1.

Before my PhD, I got a Bachelor's Degree in Speech and Language Therapy, and a Master's Degree in Health & Society. I started working as a speech therapist in Italy not long after finishing my undergraduate studies. While I was enjoying my job as a speech therapist, I also realised that I wanted to learn more about research in healthcare settings, and moved to the Netherlands where I attended a Master's Degree programme in Health and Society. This Master's programme changed my perspective on clinical care, as it allowed me to learn more about the different philosophies behind clinical practice, science, and evidence. It also shifted my attention from pathogenesis (i.e., the mechanisms that cause disease) to salutogenesis (i.e., the mechanisms that cause health, see Antonovsky, 1979) and health promotion.

For my Master' thesis, I conducted a study on the life histories of students with disabilities at Wageningen University (Dell'Olio, *et al.*, 2018), whereas my internship project was about the development of social farming in Italy (Dell'Olio, *et al.*, 2017). These two projects focused on very different topics and theoretical frameworks, yet both allowed me to develop an interest in research and qualitative methodologies, which is why I decided to pursue a PhD after completing my Master's programme.

Since the start of my PhD, I have reflected on matters on ontology and epistemology, and I have realised how positivistic my clinical orientation and education had been when I was a speech therapist. Whereas I did not consider that to be a negative thing in itself, I noticed that such orientation made me miss out on some aspects of care that would have been important to my patients, and that would have enriched and improved my treatment plans by making them more relevant to them. As a speech therapist, I would have probably thought I was person-centred, yet this PhD gradually made me question whether that was really the case. This question prompted me to further explore the concept of person-centred care in all its nuances, and its relevance to clinical practice in primary care settings and beyond.

3.1 Philosophical underpinnings of my research

In this second part of my research, I aimed to explore the knowledge work of people with long-term conditions in the context of their healthcare experiences. Therefore, I decided to adopt a qualitative approach, as it is focuses on "insight and understanding from the perspective of those being studied" (Merriam and Tisdell, 2015, p. 1).

There are many types of qualitative methods and methodologies. In the case of my study, I decided to opt for a multi-method design, by combining two qualitative methods: interviews and focus groups. To understand what this study's qualitative approach entails, I first include a description of the philosophical underpinnings of this methodology. I focus on matters of ontology, which concerns the nature of reality, and epistemology, which focuses on how knowledge is derived (Kant, 2014).

According to Grix (2002), the ontological and epistemological stances that a researcher takes during a given research project are related, as the researcher's assumptions about the nature of the phenomenon under study (ontological assumptions) and on what and how we can know about it (epistemological assumptions), guide the development of the study's methodology. Therefore, in selecting the stances that would best suit my research, I considered a number of issues.

Firstly, I recognised that my research question required an in-depth understanding of people's lived experiences, and of their perspectives on such experiences, so as to reflect on changes needed to improve person-centred care. Therefore, as regards my ontological stance, a relativist approach was not appropriate, because it postulates that reality does not exist independently of our thought, and is a subjective experience (Levers, 2013). This leads to the acceptance of a multitude of different accounts as equally valid, hence not being compatible with the applied nature of the aims of this research. Then, I considered a realist perspective, which postulates that reality exists independently of thought, and assumes that such reality can be known objectively, as it really is (Michell, 2003). However, this approach, which is referred to as naïve realism, was also not suitable for my study, whose focus is on both lived experiences and subjective meanings. Therefore, I adopted a subtle realist approach, because it holds that there is a real world that exists independently of our perceptions, yet what we can know about it is a selective representation mediated by our own perspective (Given, 2008). Subtle realism accepts alternative valid accounts of a phenomenon and rejects the possibility of the achievement of a certain knowledge of the world, though postulating that we can approach such knowledge (Hammersley, 1992; Maxwell, 2012). This stance is compatible with my study and research questions because it recognises the real, lived aspect of the healthcare experiences of people with long-term conditions, while accounting for differences in individuals' perceptions of such experiences.

Then, in considering the epistemological stance most suited to critically examine my phenomenon from a subtle realist perspective, I considered a range of approaches. A positivist approach, which assumes reality can be measured as it is static and fixed (Bunniss and Kelly, 2010), would have been inappropriate for my study, because people's experiences and perspectives are dynamic and varied. A pragmatic perspective would argue that the aim of an inquiry is not to accurately represent reality, but to achieve utility (Feilzer, 2010). In this case, the value of opinions and meanings captured through data depends on their practical consequences (Kelly and Cordeiro, 2020). However, this stance would also not be appropriate for my research, which aims to describe a phenomenon, and not to determine the value and consequences of the research data. Therefore, for my work, I decided to adopt an interpretive epistemology, as it aims to understand a phenomenon from an individual perspective (Scotland, 2012). An interpretive epistemology assumes that knowledge is grounded in experience and bound to the context in which the knower lives, hence not being generalisable (Hiller, 2016). I deemed it an appropriate approach to the investigation of my research problem, which consisted in exploring the experiences of individuals with long-term conditions to understand their knowledge work (i.e., the phenomenon) in the context of their healthcare experiences.

Therefore, my stance for this research study was that of a subtle realist ontology and an interpretive epistemology, as "our knowledge of the *real* world is *inevitably interpretive*" (my emphasis) (Frazer and Lacey, 1993, p. 182), and I set out to explore the participants' lived healthcare experiences through their perceptions and the meanings they attach to them.

3.2 Research design

In chapter 1, I presented the three aims of my doctoral research:

- To develop a critical understanding of the essential aspects of person-centred care from the perspective of people with long-term conditions.
- To systemically describe the knowledge work of people with long-term conditions in the context of their healthcare experiences.

- To critically consider whether changes in approaches to understanding and supporting patient knowledge work can foster the enhancement of person-centred care.

Taking into account the ontological and epistemological stances compatible with my enquiry, I described three pieces of research to achieve the aims outlined above:

1) A secondary analysis of existing research, in order to understand person-centred care through the healthcare experiences of people with long-term conditions. This was undertaken through a meta-ethnography, which has been presented and described in Chapter 2.
2) The conduction and analysis of interviews and focus groups, to explore the knowledge work of people living with long-term conditions in the context of their healthcare experiences. This has been undertaken through interpretive phenomenological analysis for the individual interviews, and thematic analysis for the focus groups.
3) An integration of focus groups' and interviews' data to describe a novel account of structures and mechanisms that support the knowledge work of people with long-term conditions. This was undertaken by referring to Lambert's and Loiselle's (2008) recommendations for the rigorous combination of focus groups and interview data.

After carrying out the meta-ethnography (first aim), I set out to work on the second and third aims of my study. As described above, to start working towards these aims, I decided to conduct individual interviews and focus groups. The purpose of the interviews was to achieve an in-depth and detailed exploration of patients' lived experiences (Boyce and Neale, 2006), whereas focus groups would allow for the identification of a wider breadth of data generated in a more dynamic and interactive context (Rabiee, 2004).

I now discuss in detail the rationale behind each of these methods, and my approach to interview and focus group data, including ethical clearance, recruitment, data collection, and data analysis and integration.

3.2.1 Ethical approval

A patient-public involvement (PPI) representative (and, later, a PPI panel) reviewed the study protocol (including interviews and focus groups schedules), consent forms, participant information sheet, and advertising material that I developed at the start of my PhD. Changes suggested by the PPI representatives focused on the terminology used on the study protocol (e.g., suggestion to write "health problem" instead of "disease"), and on clarifying data management plans (e.g., make explicit references to the General Data Protection Regulation on the Participant Information Sheet). Afterwards, I submitted the documentation for approval to the host institutions (Hull York Medical School and University of Hull) and then to the NHS Research Ethics Committee and Health Research Authority.

Whereas this was not a high-risk study, at the planning stage I tried to anticipate any potential ethical issues that could arise. Time and availability of people with long-term conditions was one of the ethical issues that I considered as, depending on their conditions, they could get tired or fatigued during an interview. In this case, I told every participant that they could ask for a shorter interview, and that they could decide to stop the interview at any time should they get tired or upset for any reason. However, only one participant opted for a shorter interview, though this was because of other commitments rather than fatigue.

Another ethical issue that I considered was the chance that the participant could reveal particularly serious or concerning experiences. In that case, I planned to ask for permission to escalate any issues with my supervisors or to direct the participants to any relevant services in the area. This possibility was presented in the Participant Information Sheet. However, this did not happen, although I told some participants about other patient support groups in the area when they asked if I knew any.

When considering ethical issues of their research and teaching, Blume (2017, p. 102) wrote that they were confronted with the claim that "sociologists are engaged in turning other people's experiences, other people's suffering, into the stuff of which our own careers are built." I reflected on this statement, and ultimately decided that I would follow a deontological approach to my study, by taking the participants' needs into account and not treating them as a means to an end, but always respecting their humanity (Misselbrook, 2013). For example, one participant started crying during their interview, while answering the question "How does it feel to live with a long-term condition?". Instead of continuing the interview, we stopped recording and waited together for the participant to feel better before starting again.

Eventually, my study received ethical clearance at the beginning of March 2019 (REC Reference 19/EM/0056, see Appendix D on page 263 for the approval letter). At the end of March, I also received a research passport and a letter of access to NHS primary care settings.

3.2.2 Recruitment and sampling

For the individual interviews, as I was planning to use interpretive phenomenological analysis (I describe this approach in section 3.2.4), I decided to inform my initial decision about the sample size of my study based on the methodological literature in the field of phenomenology. Still, there is no specific guidance on sample size and characteristics in scientific phenomenology (Polkinghorne, 1989). For example, different phenomenological studies in nursing included from 1 to 76 participants (Norlyk and Harder, 2010). Therefore, for the in-depth interviews, I set an initial target of fifteen to twenty participants, as I considered it an appropriate number to provide a rich description of phenomenon while being realistic in terms of time. Then, during the data collection period, I set the end of recruitment by referring to data saturation, defined as the point in which nothing new is apparent (Grady, 1998). I opted for data saturation because of its association with phenomenological study designs, by virtue of its focus on the interview processes (Fusch and Ness, 2015). In the specific case of my study, I defined it as the point in which the answers to an interview did not yield any new topics compared to the previous interviews. I checked data saturation by transcribing each interview soon after it ended, and keeping record (list) of the main topics discussed. After interviewing seventeen participants, I believed that data saturation was probably achieved. At this point, I followed Jackson's and colleagues' (2000) approach by recruiting two additional participants to ensure that data saturation was achieved. A twentieth, male participant asked me to participate after I had conducted the nineteenth interview. I decided to recruit him mainly for gender balance purposes, as I recruited more women than men for the individual interviews (I talk more about this in the following paragraphs). At this point, as data saturation was already achieved, I stopped recruiting interview participants.

As regards the sampling process, all the people who got in touch to participate in the study were offered the possibility to participate in either a focus group or an individual interview. As the participants tended to prefer to participate in individual interviews (because of their more flexible time and setting), I approached patient support groups and patient participation groups to specifically recruit focus group participants. Recruitment for focus groups and individual interviews started and proceeded in parallel, although the participants in the individual interviews were recruited more quickly than those in the focus groups.

For the individual interviews, I opted for purposive sampling to ensure I could include people who met the eligibility criteria. However, though unplanned, snowball sampling also occurred as the participants themselves offered to get in touch with other people that they believed met the eligibility criteria. Still, I ultimately decided whether to include or exclude any participants that contacted me through snowball sampling. This decision was based on data saturation as well as on the characteristics of the potential participants (i.e., whether they actually met the eligibility criteria). I looked for people of different gender, age (i.e., younger and older adults), health condition, and registered to different general practices, to allow for the collection of a diversity of experiences with knowledge work in the context of the participants' healthcare experiences.

As regards the focus groups, I aimed for three to four group discussions as such number is typically sufficient for the emergence of the vast majority of themes in qualitative studies (Guest *et al*., 2017). I opted for code saturation to set the end point for recruitment, defined as no emergence of new codes during data analysis (Hennink *et al*., 2019). In order to do this, after coding the first transcript, I recorded any new codes as I coded the following transcripts. After coding the data from the fourth focus group, I did not identify any new codes, and therefore decided to end recruitment for the focus groups.

As regards sampling for the focus groups, I used a combination of purposive sampling (three focus groups) and convenience sampling (one focus group whose participants came from two general practices who agreed to help with recruitment).

I recruited different people for the interviews and the focus groups, because I intended to keep these data collection methods distinct, with a focus on the phenomenon rather than the individuals. Still, I aimed at recruiting the same population for both methods, so exclusion and inclusion criteria for the recruitment of the study participants were the same for both the interviews and the focus groups (table 3.1).

I aimed to include adults with long-term conditions able to speak English and to give informed consent. Furthermore, the participants needed to be able to recall and talk about their healthcare experiences during the interview. Therefore, I had to exclude people with advanced stages of dementia or with severe aphasia (defined as the inability to comprehend language and/or speak, read and write).

Table 3.1. Inclusion and exclusion criteria for participation in the study.

Inclusion criteria	**Exclusion criteria**
a. Adults (age 18 and over).	a. People that do not have any long-term condition.
b. People with one or more long-term conditions (i.e., a health condition with a continuing course, or reoccurring for a long time) (Bernell and Howard, 2016).	b. People receiving exclusively telecare.
c. People able to speak English.	c. People who do not speak English hence cannot provide informed consent and be interviewed.
d. People able to participate in an interview and recall their experiences.	d. People who might not be able to give a detailed account of their healthcare experiences (e.g., people with advanced stages of dementia).
e. People able and willing to give consent.	e. People who are not willing or able to give consent.

Recruitment started upon receipt of ethical approval. I identified thirty-two local patient support and community groups, either online or through word-of-mouth, and approached them via e-mail, post, or phone, depending on which contact details were available publicly.

The e-mail/letter that I sent to advertise the study is available in Appendix E (page 266). Of these thirty-two groups, nine offered their support. One group expressed disinterest in participation. Twenty-two groups did not respond to the invitation despite a follow-up message and reminder. It is not possible to name the groups for reasons of disclosure, however all nine groups were either patient and public involvement groups, patient support groups, or charities/community groups. All were local to the region of Humber Coast and Vale. These groups offered help by either participating in my study, giving advice or networking tips, or looking for participants/advertising the study themselves. Each of the patient support groups involved was about a specific type of long-term conditions (e.g., endocrine, neurological, and respiratory conditions among others) whereas community groups were about providing healthcare and social support to the community or to specific groups of people (e.g., older people, socially vulnerable people, and so forth).

For the individual interviews, I recruited twenty participants. Ten of them were recruited through patient support groups and community groups; the remaining ten participants were recruited through snowball sampling among the participants.

The interview participants' age ranged from 44 to 75 years, averaging to 67 years. All the participants indicated to have one or more long-term conditions (table 3.2). A majority of women (n= 14) decided to participate in the interviews. I elaborate more on this in Chapter 6, section 6.3.

Table 3.2. Characteristics of study participants (individual interviews). Not all the characteristics have been disclosed because of ethical reasons. For example, for every participant, only the type of their primary health condition, as indicated by each participant, has been reported. If the participant also reported having at least another long-term health problem, this has been indicated with the expression “multiple long-term conditions”. Participants have been listed below based on interview (chronological) order.

#	**Pseudonym**	**Sex**	**Age range**	**Type of long-term condition(s)**
1	Mark	Male	50s	Neurological condition, multiple long-term conditions
2	Emma	Female	50s	Endocrine condition
3	Mary	Female	60s	Kidney disease, multiple long-term conditions
4	Jane	Female	70s	Neurological condition, multiple long-term conditions
5	Kyle	Male	70s	Heart condition
6	Victoria	Female	70s	Endocrine condition, multiple long-term conditions
7	Owen	Male	60s	Heart condition
8	Angela	Female	60s	Sleep disorder, multiple long-term conditions
9	Ada	Female	70s	Respiratory condition
10	Eva	Female	70s	Respiratory condition
11	Claire	Female	40s	Endocrine condition
12	Martha	Female	70s	Heart condition, multiple long-term conditions
13	Charlotte	Female	70s	Joint disease, multiple long-term conditions
14	William	Male	40s	Neuromuscular condition, multiple long-term conditions

Table 3.2 (Continuation). Characteristics of the study participants (individual interviews).

15	Emily	Female	60s	Respiratory condition
16	Oliver	Male	60s	Respiratory condition, multiple long-term conditions
17	Patty	Female	70s	Respiratory condition, multiple long-term conditions
18	Tessa	Female	60s	Respiratory condition, multiple long-term conditions
19	Ann	Female	60s	Respiratory condition, multiple long-term conditions
20	Thomas	Male	60s	Respiratory condition

The participants in the focus groups (table 3.3) were recruited through patient support groups and general practice surgeries. I contacted forty-one general practice surgeries via post. As I received limited response from general practice surgeries (three replied to the invitations, and two offered to help with recruitment), I decided to send direct invitations to the general practices' patient participation groups. Of the forty-one practices in Hull, ten displayed the contact details of their Patient Participation Groups on their website. I contacted these via e-mail. Two replied, and one helped with recruitment.

Eventually, twenty-two people participated in the focus groups. Men and women were equally represented (11 men and 11 women). All the participants were living with one or more long-term conditions, and their ages ranged from 61 to 81 years, averaging to 71,5 years. One carer was present during the third focus group, to assist her husband with mild vision problems, but was not a participant.

Table 3.3. Characteristics of the study participants (focus groups). As for the participants in the individual interviews, not all characteristics have been disclosed because of ethical reasons. Some participants have not indicated one primary health problem, but a series of health problems. In this case, only the expression “multiple long-term conditions” has been reported on the table. Focus groups have been listed in chronological order.

	Pseudonym, sex, and age	**Long-term conditions**
1	1) Jack, male, 70s 2) Fiona, female, 70s 3) Lorna, female, 70s	1) Endocrine condition 2) Endocrine condition 3) Multiple long-term conditions
2	1) Daniel, male, 60s 2) Liam, male, 70s 3) Laura, female, 70s 4) Lily, female, 70s 5) Nora, female, 80s 6) Alex, male, 60s	1) Multiple long-term conditions 2) Multiple long-term conditions 3) Multiple long-term conditions 4) Joint disease 5) Multiple long-term conditions 6) Multiple long-term conditions
3	1) Adrian, male, 70s + carer (carer was not a participant) 2) Erin, female, 60s 3) Samuel, male, 60s 4) Lucy, female, 70s 5) Julia, female, 60s 6) Nathan, male, 70s	1) Multiple long-term conditions 2) Multiple long-term conditions 3) Multiple long-term conditions 4) Multiple long-term conditions 5) Respiratory condition 6) Multiple long-term conditions
4	1) Lena, female, 70s 2) Cindy, female, 70s 3) Colton, male, 70s 4) Matt, male, 60s 5) Michelle, female, 60s 6) Simon, male, 70s 7) Evan, male, 60s	1) Multiple long-term conditions 2) Multiple long-term conditions 3) Multiple long-term conditions 4) Multiple long-term conditions 5) Multiple long-term conditions 6) Multiple long-term conditions 7) Multiple long-term conditions

As explained earlier in this section, recruitment stopped when I reached data saturation for the individual interviews, and code saturation for the focus groups. In the next section, I describe how I set out to collect data from the participants during interviews and focus groups.

3.2.3 Data collection

For the individual interviews, the interview setting was chosen by each participant. Almost all of the interviews took place at the participants' home, although six were conducted within the premises of the University of Hull, and one in a private, secluded area inside a public place (café). In two cases, some participants requested to be interviewed in pairs (with a friend/partner) rather than individually (this will be further explained in section 3.2.4.1). When this happened, both participants decided together where the interview would take place. As I conducted the individual interviews alone, I followed the departmental lone working policy to minimise the risks associated with lone work.

I designed the interview guide for the individual interviews (see appendix F, page 272) drawing on Seidman's (2006) guidelines for the development of phenomenology-based interviews. Therefore, the interview guide covered three aspects: the first part of the interview focused on the participant's life context. In this case, I asked the participants how it is to live with a long-term condition, and if/how their life changed since becoming ill. Then, the second part focused on the details of their experiences (with specific reference to primary care experiences). Finally, in the third part I explored the participants' meanings and reflections on such experiences (for example, I would inquire into the participants' thoughts or feelings about an experience). The interview covered topics such as experiences with general practice services and managing a long-term condition. Most of the questions included in the interview guide focused on lived experiences ("What happened/what did you do" questions), and were open questions, to encourage the participants to talk at length about their experiences. Probing techniques that aimed to delve deeper into the participants' experiences were also included in the interview guide. Examples are clarifications ("can you explain…") and extensions ("can you tell me more about/can you give me an example of…”). Questions about the management of long-term conditions were included to understand the participants’ knowledge work in the context of living with an illness (e.g., what it entails, what hinders/facilitates it, and the reasons why the participants engage in managing their own conditions). The interview guide was piloted with a heart disease patient, and it was amended to make the questions easier to understand for the participants.

As regards the focus groups, two were conducted at the University of Hull, one at a general practice surgery, and one at a place where the participants in the focus group used to meet on a regular basis. A focus group assistant (Dr. Efioanwan Andah) was always present to take notes or assist with the facilitation of the discussion.

The focus groups’ interview schedule is available in appendix G (page 274). Like the individual interviews guide, it aimed to explore experiences with general practice services, but the emphasis was on sharing different experiences and exploring the variety of people’s opinions and perceptions about such experiences. I developed the focus groups schedule following Krueger’s (2002) recommendations, which suggest starting with general questions (e.g., questions about positive and negative aspects of general practice), and gradually ask more specific questions (e.g., questions about personal definitions of person-centred care). Questions about experiences (e.g., can you describe a positive/negative experience with general practice?) were accompanied by questions to stimulate thought, debate, and reflection, such as “Why do you think this is important?”, “Does everyone else agree?”, “anyone else had a similar/different experience?”. With this aim (i.e., to stimulate thought and reflection), the interview guide also included a vignette exercise (also available on page 275 in Appendix G). This exercise consisted in presenting the participants with a relatively complex clinical situation, and asking them what they would do if they were a GP. I chose this specific vignette activity to explore the participants’ priorities and preferred communication styles during clinical encounters. I designed the vignette so that it would fit with both an interpretivist epistemology and a subtle realist ontology. The vignette would draw on people’s perceptions of what a clinical encounter looks like, thus being based on subtle realism by presenting a realistic example of a situation that the participants have already experienced, hence allowing for the exploration of real-life judgments (Harrits and Møller, 2020). On the other hand, it followed an interpretive epistemology because it asked for the participants' interpretations of realistic scenarios, and in particular for a shift in perspective from their own to that of a doctor.

I piloted the focus group guide with a group of three participants. I considered the methodological implications of including data from the pilot focus group as part of the analysis, and eventually decided to include them. Firstly, the pilot interview was recorded, and consent for participation was taken regularly. Secondly, the participants were legitimate, as they met all the inclusion criteria. Also, the data from the pilot focus group did not differ from the data obtained from the other focus groups, as the only amendments that I made to the focus group interview guide after piloting it were to shorten it, by removing some questions, hence the questions asked were the same across the focus groups (with circumstantial variations). Finally, pilot data provide important information in their own right (Beebe, 2007), and I believed that the data from the pilot focus group was rich and relevant enough to warrant inclusion. The duration of the focus group interviews ranged from to 60 to 114 minutes, averaging to approximately 87 minutes.

As regards individual interviews, I took field notes to document contextual information (Phillippi and Lauderdale, 2018). These usually included basic information (e.g., participants' age and gender, diagnosis, and general practice where they were registered) and context, participant, and interview information (e.g., relevant details about the location, about the participant health status and ability to participate in the interview, about nonverbal behaviour, and so forth). The duration of the individual interviews ranged from 44 to 106 minutes, averaging to approximately 64 minutes. During the focus group discussions, note-taking was done by the focus group assistant.

Both interviews and focus groups were audio recorded. I always started transcribing immediately after each interview, or within the next two days. I formatted the transcripts so that they could convey more information than just text about what was said. Therefore, in the results chapters, each quote is followed by the participant's pseudonym, sex (F for female and M for male), age, and type of long-term condition. In the case of the focus groups participants, each pseudonym is preceded by "FG" and the focus group number (e.g., "FG1"), as reported on table 3.3. I reported the participants' quotes verbatim, though with some occasional modifications. For example, elisions from the original quote are represented by a set of square parentheses, namely […]. When the decontextualised quote was not clear enough, or something needed to be anonymised, I made an addition/replacement between square parentheses (as in [this example]). When the participant gesticulated or expressed feelings through non-verbal signs, I noted down the action in square parentheses, and in italics (e.g., [*laughs*]). Participant's emphases (e.g., moments in which the participant emphasised their tone while saying something) are <u>underlined</u>. Finally, any of my comments and questions made during the conversation are indicated by the letter I, which stands for 'Interviewer'.

3.2.4 Data analysis

I employed two different approaches to data analysis. For the individual interviews I adopted an ideographic approach based on interpretive phenomenological analysis, which focuses on individual experiences and meanings; for the focus groups, I adopted a cross-cutting approach based on thematic analysis, which focuses on breadth and pattern identification across the data. In the next sections, I explain how both are compatible with the subtle realist/interpretivist stance of my doctoral research. In this section, I focus on data analysis of the individual interviews, whereas the analysis of the focus groups data is described in the following section. In section 3.2.5, I describe how I integrated the data from these two approaches.

3.2.4.1 Individual interviews

As regards the individual interviews, I decided to adopt a phenomenological perspective to allow for in an in-depth exploration and description of the participants' knowledge work in the context of their healthcare experiences. Phenomenology in health and social research is regarded as

> "the study of human experience and of the way things present themselves to us in and through such experience" (Sokolowski, 2000, p. 2)

and aims to understand phenomena through the meaning that people attach to their experiences (Bogdan and Biklen, 1992) .

The phenomenological tradition started with Husserl, a philosopher and mathematician who presented phenomenology as a "new, critical and rigorous science" whose task is to 'describe' phenomena by focusing on what is given, instead of what is expected (e.g., theoretical assumptions) (Zahavi, 2003, p. 44). Heidegger, who was one of Husserl's students, leaned towards what some critics defined a more interpretative phenomenology, the aim of which shifts from describing essences to understanding meanings, hence it presumes and even encourages prior understanding (Reiners, 2012).

Phenomenology was introduced to the social sciences by Schutz (1972), after which it was adopted more widely in other fields, including that of nursing sciences, though with some adaptations that were seen by some critics as a disconnection from the original phenomenology as intended by Husserl and Heidegger (Crotty, 1996; Paley, 1997; Paley, 1998) .

To date, many different types of phenomenology exist (Embree, 1997), and have contributed to the development of qualitative research through their approaches to the study of human experience (Holloway, 2005). For my study, I wanted to adopt a phenomenological approach to data analysis that was focused on sense-making, as I wanted to understand the knowledge work of people with long-term conditions from their own perspective, and to be consistent with my subtle realist/interpretive stance. I found this could be achieved through interpretative phenomenological analysis (IPA), an analytical approach that allows for a detailed and nuanced analysis of interview data, and aims to elicit the way in which people make sense of their lived experiences (Smith, 2004; Smith, 2018). The link between IPA and an interpretivist epistemology can be made not only through the "interpretive" label in the name itself, but also because, just like IPA focuses on sense and meaning making, the interpretivist epistemological paradigm poses that situations and phenomena can be understood through the meaning they hold for the participants (Pascale, 2010). From an ontological perspective, phenomenological approaches favour a subtle or critical realist paradigm (Finlay, 2012), and IPA has been found to lean towards a broadly realist ontology, which makes it compatible with applied concerns (e.g., applied health research) (Reid *et al*., 2005).

Although the use of IPA is more frequent in studies with a small number of transcripts (usually five to ten transcripts), using IPA with a relatively large number of transcripts is possible, if the data analysis plan allows for the exploration of a specific experience, or phenomenon, that is common to all the participants (Smith *et al*., 1999) (in the case of my study, this would have been the knowledge work of the participants in the context of their healthcare experiences). Since twenty people participated in the individual interviews, but four of them were interviewed in pairs, I had to analyse 18 transcripts. I developed an analysis plan following the guidelines for using IPA with relatively large datasets proposed by Smith and colleagues (1999), which I describe more in detail in the next paragraphs. I present a more detailed description with examples of the analysis process in Appendix H (page 277).

The participants that were interviewed in pairs were known pairs (i.e., a couple of friends, and a husband and wife couple), and asked to be interviewed together because they found it more feasible. Data collected from dyadic interviews allow for the exploration of overlaps, contrasts, complementarities and (dis)agreements among the participants (Eisikovits and Koren, 2010). Whereas dyadic interviews recognize “the value of interconnected relationships”(Caldwell., 2014, p. 492), the focus of my study was not on the participants’ relationships or on their shared experiences, but on individual experiences with clinical consultations. Still, dyadic interviews in this study were helpful when one of the people in the pair would remember something that the other forgot to mention, thus allowing for the collection of data that would not have been collected otherwise (Morgan, *et al*., 2013).

My initial aim was to become familiar with the data. I listened to all the recordings twice, the first time to transcribe the conversation, and the second time to polish the transcript and take notes. Then, I transferred each transcript to its own, dedicated NVivo library. I did this to preserve the idiographic focus of phenomenology from an early stage of data analysis, and avoid codes cross-contamination between transcripts.

Then, I engaged in a preliminary, inductive coding phase, in which I mainly used descriptive codes. Smith (1999, p. 229) specifies that it is not necessary to go in too much detail during this phase, hence coding can be broad and unrefined, and can focus on the main/key concepts, as it is acceptable to code longer sentences or small paragraphs.

The aim of this preliminary coding stage was to identify topics of interest to be analysed through in-depth analysis at a later stage. I did this by developing mind-maps as I examined any relationships between codes across all transcripts.

Then, I decided on a topic to investigate through further, in-depth analysis. This decision was informed by the findings of my systematic review (see Chapter 2), which identified instances of epistemic injustice in the clinical consultation and highlighted the importance of person-centred care not as a solitary endeavour, but as an achievement of patient, doctor, and organisational system. Therefore, I decided to further explore the participants' experiences of clinical encounters with clinicians, as well as their thoughts and feelings regarding such experiences. I also decided to analyse their experiences with the management of their long-term conditions, not only because such experiences were usually related to their clinical encounters, but also because they would contribute towards my aim of systemically describing the participants' knowledge work.

I reread the transcripts again, identifying all the instances in which the participants described an encounter with a clinician, and/or the management of their conditions. Then, I extracted related excerpts from the transcripts by copying and pasting them on a new document, waiting to be coded anew. When in doubt, Smith and colleagues (1999) suggest erring on the side of overinclusion in this phase. The new document consisted of a table in which each participant was assigned their own row. I wrote down the pseudonym of the participant, and their age, gender and long-term conditions in the left-hand column, and pasted the relevant excerpts from that participant's transcript in the right-hand column.

In this phase, the corpus of data should be intensively examined by coding in more detail (Smith *et al*., 1999). I thus engaged in in-depth coding of the excerpts in the style of IPA, by coding the text on one side (margin), and writing comments (e.g., reflections and hunches) on the other side. My supervisors, Prof. Joanne Reeve and Dr. Paul Whybrow, both coded one transcript each. We decided it was a better idea, in their case, to analyse an entire transcript instead of excerpts, so that they could be aware of the whole context of the interview. Discussions with them aided my interpretation as we compared our decisions via e-mails and supervision meetings. After coding each account, I also wrote a brief thematic summary of such account, in which I highlighted key concepts and emerging themes in bold. I included an excerpt from a thematic summary in Appendix H (page 277).

I used those summaries to identify the shared concepts and themes across the dataset, and developed a raw thematic summary, including preliminary themes and sub-themes. I created a new document with all the themes, sub-themes, and their corresponding definitions and quotes, which I proceeded to code again, so that I could identify relationships between themes and sub-themes. This was an iterative process during which I kept writing and sharing my interpretations and preliminary findings with my supervisors.

As I looked for the shared aspects of the participants' healthcare experiences, I found both similar and contrasting examples. From a phenomenological perspective, comparing different experiences helps the researcher identify the invariant structures of phenomena, namely those aspects that remain constant and thus characterise the phenomenon (Eberle, 2014). This way, I identified the constant aspects of the participants' knowledge work in the context of their healthcare experiences, and developed the final list of themes from the individual interviews.

3.2.4.2 Data analysis: Focus groups

Focus groups are group interviews whose distinct features are the group dynamics and the breadth of data generated through the interaction of the members of the group (Rabiee, 2004). I carried out the analysis of the focus groups data through thematic analysis, which is one of the conventional methods of data analysis in focus groups (Wilkinson and Silverman, 2004). I conducted the analysis through a six-step process, outlined by Clarke and Braun (2015). They described the approach that they developed as independent from any particular epistemological and ontological base, making it a flexible approach to answer a variety of research questions. Therefore, I decided to adopt it for the analysis of the focus groups, as thematic analysis is particularly suited to identify patterns in the data (Maguire and Delahunt, 2017). In particular, I aimed to identify a range of views on knowledge work in healthcare settings, on person-centred care and on the wider healthcare context. I describe the analysis process below.

Step 1: Become familiar with the data

This starting point resembles the first step described for the individual interviews in section 3.2.4. Therefore, at this stage, I familiarised myself with the data by listening to the focus groups recordings twice. Additionally, I read all the focus groups' transcripts while writing down notes and observations prior to the start of the analysis.

Step 2: Generate initial codes

As suggested by Maguire and Delahunt (2017), after completing the first step, a researcher might already have an initial idea about codes. Still, as for the interviews, and in line with an interpretive framework, coding was inductive, hence it was not guided by any a-priori index. Therefore, the second step consisted in coding segments of the transcripts that I considered meaningful for the research question and aims.

In order to do this, I transferred all the transcripts to NVivo, in the same library, as I thought that could help me identify any patterns, for example by comparing codes from one transcript to another (where appropriate), but also highlight any differences across the dataset from an early stage. At this stage, I was also checking for code saturation (see § 3.2.2, page 67), coding examples of both lived experiences and opinions/perceptions of healthcare services. Clarke and Braun (2015) identify both semantic codes (i.e., surface level codes that capture what is explicitly stated) and latent codes (i.e., deeper level codes that capture meanings and ideas). At this stage, my codes were mainly semantic. Examples of semantic codes at this stage were "respectful explanation" and "lifestyle advice" in the context of the participants' perspectives on how to handle complex clinical situations. However, I occasionally used latent codes at this stage. For example, "avoidable suffering" was a latent code that I used in the context of the participants' views about the (perceived lack of) competence of health professionals.

Step 3: Search for themes

At the end of the previous step, I had a list of codes (codebook) from all the transcripts, and some ideas for preliminary themes. Clarke and Braun (2015) wrote that the search for themes must be characterised by a focus on data that are meaningful and important for answering the research question. In order to do this, I focused on understanding how multiple codes could fit together to develop a theme, and so I developed a preliminary thematic index. As most codes were semantic, the preliminary themes that I developed at this stage were predominantly descriptive. Examples of the preliminary themes at this stage were "practice's characteristics" and "knowledge dimension of healthcare experiences".

Step 4: Review themes

Clarke and Braun (2015) suggest reviewing the themes at two levels: checking the theme against the data, and checking the themes against the dataset. This two-level interpretative exercise of zooming in and out between the parts and the whole is referred to as the hermeneutic circle (Willig, 2014). For the first level of review, I transferred the themes and sub-themes, along with the corresponding quotes, on a new document. Upon doing such work, I re-read and recoded the quotes within each theme and sub-theme. This way, I realised that there were some overlapping sub-themes, and merged them into larger sub-themes (for example, I merged two sub-themes that both related to "reassurance"). I also renamed other themes, or refined their definitions, so that they could better reflect the data that they encompassed. For example, I changed the sub-theme "knowing the patient" to "knowing the person", as the data it encompassed were indicating that the participants wanted their GP to know how they were doing and their personal circumstances, other than their medical histories.

For the second level of review, I had to check the themes against the whole dataset. I did this by going back to the original dataset (the transcripts on NVivo) to see whether the newly refined themes and sub-themes still made sense in the light of the whole dataset, and if any uncoded data needed to be coded under any of the new themes. By doing this, I found more instances of the refined themes in the data. For example, I initially developed the raw, descriptive theme "handling clinical encounters", which I then renamed as "negotiating complex clinical situations" upon checking the themes against the data (first level of review, as described in the previous paragraph). When going back to the entire dataset, I found even more instances of experiences of negotiating with health professionals, that I did not code as such previously.

After this process, I had a refined set of themes, whose relationships needed further definitions and explanations.

Step 5: Define themes

At this stage I focused on defining themes, sub-themes, and their relationships. I did this by writing thematic summaries for each theme and sub-theme on a Word document, and writing any further interpretations and comments about their relations on the margins. For example, themes like "discovering the 'hidden obvious'" and "a territory of uncertainties" were put in relation through their epistemic focus, and I put them under the umbrella of "epistemic interpretations of primary care experiences". Throughout this process, I went back again to step 4, to review the final themes against each other, and against the dataset. Similarly, step 5 also overlapped with step 6 ("producing the report", described in the next section), as writing down my interpretations and descriptions of the quotes also led me to keep redefining themes and sub-themes iteratively, until new iterations of this process did not produce any further insights, and I could develop a final and defined set of themes.

Step 6: Producing the report

The last step of data analysis described by Clarke and Braun (2015) consists in writing a report of the findings. I wrote this report in the style of a thesis chapter, with participants' quotes accompanied by my descriptions and interpretations. As for the individual interviews, this report was discussed with my supervisors during supervision meetings, leading to further reviews of the themes and sub-themes as described in the previous section. Once all the themes were clearly described and related, I used that report to assist the integration of the focus groups and individual interviews data. I describe this process of integration more in detail in the next section.

3.2.5 Integration of individual interviews' and focus groups' data

I integrated the individual interviews' and focus groups' data in order to achieve the second and third aims of my study. Whereas the individual interviews provided insights into the participants' knowledge work and their lived healthcare experiences, the focus groups provided insights into the participants' perceptions and beliefs on such knowledge work and experiences, as well as on the wider healthcare context. Therefore, I planned to treat those datasets as mutually informative, as seeking to understand multiple dimensions of a phenomenon through the integration of findings assumes that each method contributes to our understanding of different parts of that phenomenon (Adami and Kiger, 2005). In the case of my study, this was possible because focus groups are particularly useful at cataloguing the range of participants' experiences, while individual interviews can contribute to a detailing of such experiences (Moezzi, 2007).

When I planned the integration of the interviews and focus groups data, I referred to the observations by Lambert and Loiselle (2008) on the rigour of the combination of qualitative data. Their first observation was that the rigorous combination of focus groups and individual interviews can lead to a "productive iterative process” (Lambert and Loiselle, 2008, p. 231). In order to achieve this, I started by framing both the interviews and the focus groups within an interpretive epistemology and a subtle realist ontology, as described in this chapter. Then, I compared individual interviews’ and focus groups’ transcripts, identifying two main differences between them: (1) whereas the individual interviews emphasised lived experiences, the focus groups emphasised opinions and perceptions; and (2) whereas the focus groups included a breadth of answers to the same question, the individual interviews included more detailed, single answers. Considering this, I decided it was appropriate to treat the individual interviews’ data as the principal dataset, as it was the dataset providing more detailed insights in the knowledge work of the participants in the context of their healthcare experiences. Consequently, I treated the focus groups’ data as a complementary dataset, potentially adding, through the analysis of the participants’ beliefs and opinions, new perspectives to understand the phenomenon explored in detail by the individual interviews.

The second and third observations by Lambert and Loiselle (2008) were that the rigorous combination of interviews and focus groups data can lead (2) to the identification of further characteristics of the phenomenon, and (3) to data convergence, namely a coherent description of the phenomenon. In order to achieve such nuanced, coherent description, I started the data integration process by charting themes, hence creating a table with the focus groups’ themes and sub-themes, and one with the interviews’ themes and sub-themes. Then, I started looking for any potential relationships or similarities between them.

To understand how themes from different datasets could contribute to each other, I went back to the transcripts and compared interviews’ and focus groups’ quotes from similar themes. For example, I checked whether quotes in the “Negotiating knowledge” sub-theme (individual interviews) and quotes in the “Reciprocity and togetherness” sub-theme (focus groups) could inform each other. I decided to compare these two sub-themes because they both described the interactions between doctors and patients. In this case, an example in which the breadth of the focus groups’ findings provided new angles to understand the participants’ knowledge work in the context of the negotiations with their doctors was the description of the doctor's "listening". In particular, some of the experiences of the participants in the individual interviews highlighted their disappointment at not being listened to by their doctors, because they believed that their illness experience provided them with relevant knowledge. However, during one of the focus groups, one participant explained that it is exactly because patients think that doctors have valuable knowledge, that they want them to listen, thus showing that 'being listened to' was important not only because of how much the participant valued their own knowledge, but also because of how much they valued the doctor's knowledge. This insight contributed to the definition of the mutually enriching character of the patient's and the doctor's expertise during the clinical negotiation, and is one example of how different methods can provide for a more nuanced understanding of the phenomenon under investigation.

By engaging in this process of comparison between similar (sub-)themes, and exploration of different and similar perspectives, I developed a final set of findings, represented by four main themes: (1) learning by exploring, (2) acquired experiential knowledge, (3) challenges to knowledge integration, and (4) the clinical negotiation with knowledge. I describe these themes in detail in Chapters 4 (themes one and two) and 5 (themes three and four). However, before presenting the findings of my work, I explain how I assessed its quality in the next section.

3.3 Assessing the quality of my work

Whereas there is no single consensus on how to best assess the validity of qualitative research (Russell and Gregory, 2003), subjecting research to critical scrutiny is important to evaluate the robustness of the findings (Horsburgh, 2003). However, prescriptive, standard criteria for assessing the quality and rigour of knowledge generation can be counterproductive in the context of an interpretive qualitative methodology, as they risk compromising the uniqueness of its contributions (Barbour, 2001). As a subtle realist perspective denies the possibility of the achievement of certain knowledge, measuring the findings' closeness to the "truth" would not be an appropriate indicator of quality in this study. However, as Krefting (1991) observes, the rigour of qualitative research can be established through a flexible approach to quality assessment, which looks at methodological strategies in order to establish trustworthiness.

Therefore, drawing on my research stance, I decided to adopt Whittemore's and colleagues (2001) criteria for validity in qualitative research to evaluate the quality of my work, as they allow for a flexible approach to quality assessment, characterised by the adoption of primary and secondary quality criteria. According to Whittemore *et al*. (2001), primary criteria (credibility, authenticity, criticality, and integrity) are necessary to all qualitative inquiry, while secondary criteria (explicitness, vividness, creativity, thoroughness, congruence, and sensitivity) provide further benchmarks of quality, and their application is flexible depending on the investigation.

The first primary quality criterion is credibility. Credibility defines whether the findings accurately represent the experience of the participants (Whittemore *et al.*, 2001). One strategy proposed by Lincoln and Guba (1985) to establish credibility is member checking, whereby study participants comment on the extent to which research summaries or analysed data and reports reflect their views, feelings, and experiences (Harper, 2012). Triangulating data, methods, theories, or investigators is another way assess the credibility of the findings by checking their confirmability (Krefting, 1991). Finally, another strategy to enhance the accuracy of the findings of interviews and focus groups is the recording and transcription of research data, as they capture the actual statements of the research participants.

The second validity criterion is authenticity, which represents the extent to which subtle differences between the participants' perspectives have been portrayed accurately, and the researcher has influenced the research process (Lincoln and Denzin, 1994). Considering my study's interpretivist perspective, which emphasises the role of the researcher's interpretation throughout the analysis process, I therefore decided to adopt an inductive approach to both interviews and focus groups, while actively seeking and observing conflicting experiences and perceptions in my dataset (Johnson and Rasulova, 2017).

Then, whereas criticality refers to the reflexivity of the researcher, and the critical analysis of all the aspects of an inquiry (Marshall, 1990), integrity refers to the recursiveness of the quality assessment strategies, as well as the humble presentation of the findings. Therefore, research strategies that can enhance a study's criticality are the adoption of a reflexive approach and/or the application of appropriate quality criteria to assess the rigour and robustness of the findings (Whittemore *et al*., 2001). In line with the principle of integrity, the researcher has to engage in this critical process throughout the study and use evidence to critically reflect on their findings in the context of the wider literature.

After describing the primary validity criteria, I now provide an overview of the secondary validity criteria of qualitative research.

Explicitness refers to "the ability to follow the interpretive effort of the investigator" (Whittemore *et al*., 2001, p. 531). To achieve explicitness, it is important to document the research and analysis process as well as the decisions made throughout such process. Explicitness is particularly important in phenomenology-based studies, which aim to describe a phenomenon from the perspective of the people who have experienced it, hence transparency of data collection tools as well as the investigator's research judgement are paramount to the assessment of this criterion. Therefore, I aimed to achieve explicitness in my study by keeping records of the project plan as well as of the data analysis process (of which I provided examples in Appendix H, page 277)

Vividness is another important criterion in phenomenology-based studies, as it consists in the presentation of thick and faithful descriptions of the phenomenon (Whittemore *et al*., 2001). Burns' (1989) proposed strategies to achieve vividness include the provision of a clear and detailed description of the participants' characteristics and circumstances, an understanding of the study context, and skills in writing a descriptive narrative. For my study, I aimed to achieve vividness by inquiring and probing about the lived experiences of the participants (with the interview and focus group guides available in Appendices F and G respectively) and report them in the results chapters along with descriptions and interpretations of the participants' accounts.

Creativity is represented by novel methodological approaches or innovative ways of presenting the findings (Whittemore *et al*., 2001). Creativity has been found to make research more engaging for the people involved, and is usually reflected in the study's methods (e.g., through the collection of photography or artwork) (Deacon, 2006). Creative approaches that I used in my study include imaginative variation during the individual interviews (i.e., reflecting on the same phenomenon in a different scenario) (Moustakas, 1994); and a vignette exercise to ask the participants to comment on a fictional situation during the focus groups.

Another secondary criterion is thoroughness, which refers to how comprehensive the analysis and sampling processes have been (Whittemore *et al*., 2001). This is not only reflected by the characteristics of the sample and the data analysis process, but also by a comprehensive depiction of the phenomenon under study, which is manifest through a thorough exploration of the meaning of the themes and of their relationships.

Congruence refers to how well the study research questions, methods and findings fit together, as well as how well the study findings fit in the context of the wider literature (Whittemore *et al*., 2001). Strategies to achieve congruence include the design of a research methodology that allows for the investigation of the phenomenon while being compatible with the study's epistemological and ontological stances, and a critical interpretation of the findings in the light of the wider literature.

Finally, the last secondary criterion for the validity of qualitative research is sensitivity, which determines if and how the study takes into account ethical and contextual issues (Altheide and Johnson, 1994). This can be reflected by the extent to which the research benefits the participants, or the wider context, and demonstrates the application of moral and ethical principles in its design and conduction (Whittemore *et al*., 2001).

Upon reflecting on the criteria described above, I outlined a series of steps, processes, and activities that I used to both check and achieve quality in my work. Whereas these are summarised in table 3.4, I provide a critical review of their application in Chapter 6 (§ 6.3).

Table 3.4. Summary of the application of quality criteria to my research (Whittemore *et al*., 2001).

Primary criteria	**Application to my research**
Credibility	Fieldnotes to record contextual and non-verbal information; audio recordings of individual interviews and focus groups with prompt and verbatim transcriptions; double coding (with supervisors) on a sample of transcripts.
Authenticity	Inductive approach to data analysis for both individual interviews and focus groups; coding of individual interview transcripts in a dedicated NVivo library; analysis of contrasting experiences and perceptions both within and between datasets.
Criticality	Reflexivity; expert (supervisor) checking of data analysis and interpretation; adoption of quality criteria to assess the robustness of my findings.
Integrity	Writing a study protocol; research process critically examined on a regular basis through supervision meetings and thesis advisory panel meetings; use of evidence to reflect on findings (Chapter 6).
Secondary criteria	**Application to my research**
Explicitness	Documenting the analysis process (Methodology chapter); providing detailed descriptions of data analysis and research judgments (Appendix H, page 277), including code generation and theme development, checking and refining.

Table 3.4 (Continuation). Summary of the application of quality criteria to my research (Whittemore *et al*., 2001).

Vividness	Multiple iterations of data analysis; narrative presentation of the findings accompanied by thematic maps; description of the participants' relevant characteristics; inclusion of verbatim quotes including non-verbal behaviour and accompanied by contextual descriptions and interpretations.
Creativity	Prompts for creative reflection incorporated in the interview guides, namely use of imaginative variation during the individual interviews; and proposing a focus group exercise in which the participants pretend to be a GP.
Thoroughness	Conduction of interviews and focus groups; purposive, snowball and convenience sampling of participants who all had experience with the phenomenon; multi-stage approach to data analysis which led to the identification of clusters of topics; integration of focus groups and interview data by focusing on their complementarity.
Congruence	Explicit definition of ontological and epistemological stances at the outset of the study; design and adoption of methods compatible with such stances.
Sensitivity	Writing a study protocol including methodological, ethical and practical considerations; review of study documentation from a PPI panel; applying for and receiving ethical approval from the University of Hull, the Hull York Medical School, and the NHS Research Ethics Committee; presentation of findings' implications for research, practice and education.

After providing an overview of my study's methodological approach, and of my strategy for the quality assessment of the robustness of my findings, in the next chapter I present the findings of my empirical work, which address the second and third aims of my study: (1) to systemically describe the knowledge work of people with long-term conditions in the context of their healthcare experiences;

and (2) to critically consider whether changes in approaches to understanding and supporting patient knowledge work can foster the enhancement of person-centred care.

Chapter 4 – Describing the participants' knowledge work in the context of their healthcare experiences

In this and the next chapter, I present the findings of the interviews' and the focus groups' integration. As discussed in Chapter 2, my meta-ethnography about the healthcare experiences of people with long-term conditions identified three aspects that describe person-centred care: epistemic, relational, and organisational. These findings highlighted the previously underexplored epistemic issues that patients face while attending healthcare services. The aims of data collection in this second part of the research were to get first-hand insights into the knowledge work of the participants in the context of their healthcare experiences, and then reflect on how changes to approaches to patient knowledge work in clinical settings can strengthen person-centred care.

In Chapter 3 (section 3.2) I have described the multi-stage approach to my analysis: an idiographic analysis of interview data, a thematic analysis of focus groups data, and an integration of the two data sets. In this chapter I present the overall findings from that work – the development of four themes: (1) learning by exploring, (2) acquired experiential knowledge, (3) challenges to knowledge integration, and (4) the clinical negotiation with knowledge. As I discuss in Chapter 6, these feed into the basis for my key new construct: namely that of epistemic reciprocity as a core component of successful person-centred care, and a principle that guides the clinical negotiation and fosters the co-creation of new knowledge of patient experience and need through the interactive knowledge work of both patient and doctor.

I have divided the findings into two chapters. In this chapter, I present the first two themes, namely 'learning by exploring' and 'the participants' acquired experiential knowledge', which give an overview of the person at the centre of person-centred care: a person who engages in learning by exploring to support their own health, and who perceives their knowledge to be both valid and relevant for clinical encounters. In the next chapter, I describe how that knowledge is used in the context of healthcare consultations through a presentation of the two final themes: the third theme ('Challenges to knowledge integration') elaborates on challenges to knowledge integration through a discussion of the participants' attempts to bring their knowledge to primary care settings, in a context perceived as limiting their opportunities for information exchange. I describe organisational barriers and conflicts arising when the participants' own information was for them unjustly assessed. Then, I present the fourth theme, the 'clinical negotiation with knowledge', namely a mutual effort of both patient and doctor to explore and integrate different types of knowledge while making sense of the patient's complex experience. I provide an overview of these themes in table 4.1.

Table 4.1. Themes' list and definitions.

Theme	**Definition**
Learning by exploring	This theme describes the moments in which the participants learned more about their condition(s) through the exploration and purposeful investigation of their own condition and medication, with or without input from a healthcare professional.
The participants' acquired experiential knowledge	This theme identifies the characteristics of the knowledge that the participants acquired through their illness and healthcare experiences. This experiential knowledge was exclusive, functional, and unique.
Challenges to knowledge integration	This theme describes the participants' accounts of trying to bring their acquired experiential knowledge into the clinical consultation. It shows how challenges to knowledge integration during clinical consultations were due to organisational restraints and/or conflicts arising from competing types of knowledge.
The clinical negotiation with knowledge	This theme explains how successful integration of different types of knowledge occurred through a negotiation with knowledge characterised by four different, but related moments: active exploration, amplified listening, and reciprocal inquiry.

As described in the previous chapter, my interview dataset includes the stories of 20 people living with long term conditions, with an age range of 44 to 75 years.

The focus groups data set, on the other hand, includes the views of 22 people living with long-term conditions, their age ranging from 61 to 81 years old.

In the first part of this chapter, I describe the participants' knowledge work through their learning journey, a journey of exploration in and around their long-term conditions, driven by different purposes, but with a commonality laying in the participants' sense of direction (i.e., to move forward, to "go somewhere"). I start by introducing the theme 'learning by exploring', which describes how the participants' learned more about their health conditions. Afterwards, I present the theme of 'acquired experiential knowledge', which describes the characteristics and uses of the knowledge that the participants gained throughout their illness and healthcare experience.

4.1 Learning by exploring

The theme 'learning by exploring' is defined by the moments in which the participants learned more about their condition(s) through the exploration and purposeful investigation of their own condition and medication, with or without input from a healthcare professional. I developed this theme by analysing the participants' accounts of what they did to deal with their conditions and their treatment. This effort was particularly evident through their drive to take care of themselves, exemplified by personal goals such as protecting their health, preventing worsening the condition, or improving their quality of life. The analysis described three sub-themes, which define the participants' main learning practices: information-seeking, experimenting, and reflection. I present these sub-themes more in detail in the next sections.

4.1.1 Information seeking

Several participants reported seeking information about their conditions to learn more about them or because they were unhappy with the advice received from health professionals. They described different factors prompting the search (including feelings of abandonment and doubt), but a common outcome was an attitude towards learning and seeking information independently.

This was the case of Charlotte and Angela, who experienced different problems yet described similar reasons for looking for information on their own. In the following excerpts, Charlotte was telling me how she manages her arthritis on a daily basis, implying that this was thanks to her own information seeking efforts, rather than the doctors'. Similarly, Angela was looking for information about her condition because she could not get professional help, although this did not help her as much as she hoped.

> Charlotte: They do recommend you don't [eat certain things] if you have arthritis […].
> I: Was it the doctor who recommended this?
> Charlotte: No, it's just what I've read. Because the doctors don't really tell you how to manage things, usually you have to… […] my daughter was ill for ten years and we had to, we've got no help from the doctors whatsoever, so we just read about it and managed the best we could. […] But you find out a lot of things yourself. I think if you're diabetic or something like that you usually get a diet sheet. But, with arthritis, you're rarely told that you shouldn't eat certain things. […] You have to look it up yourself, yeah. – *Charlotte, F, 70s, arthritis, multiple long-term conditions*

> I've found no help from the medical world, apart to relying on thinking things through for myself, and finding out what might be helpful and what isn't, I have still not solved it [*laughs*]. I can't stress enough the desire to get professional help. […] I'm still convinced [these remedies] won't help, because it's something lacking in my chemical system, in my head […] Well, that's a guess, it's just my guess, I've read up books, something, I'm just walking in the dark. – *Angela, F, 60s, sleep disorder, multiple long-term conditions*

In the previous examples, Charlotte's and Angela's narrative is one of abandonment, of being left alone without knowing how to manage their condition (e.g., what not to eat when one has arthritis) or understanding its causes (in

Angela's case). Charlotte also mentions that people with a different condition (diabetes) receive better care, recognizing a form of inequality in the provision of healthcare based on one's type of illness. On the other hand, although she was looking for help within healthcare settings, she did not give up when she could not find any, making hers also a narrative of initiative. Charlotte emphasises that it is the people's responsibility to look for information ("you have to"), but also implies that she had no other choice but to do so. Similarly, Angela indicated she would have preferred to get professional help instead of engaging in information seeking on her own. Still, if Charlotte found some resolution in her information-seeking behaviour (looking for dietary advice), the same did not happen to Angela, who was still looking for a cause of her sleep disorder at the time of the interview. Whereas Charlotte and Angela talked about how they looked for information outside of clinical consultations, Jack described how this attitude is crucial during the clinical consultation as well.

> I hear people say: "Well, I went and what the doctor told me is not what I wanted to know", and I say: "Well, did you ask the question?" [they say:] "No, he should know, he's a doctor!" [*laughs*] So people do go with a negative attitude and come out with not what they wanted, but if you go in quite open, and you say, "this is my problem" […] it's as simple as that. – *FG1, Jack, M, 70s, endocrine condition*

Here, like Charlotte, Jack also conveys how it is the patient's responsibility to look for the information they want, yet he focuses on the inquiring attitude of people with long term condition, which has to be clear about what is needed, and open to dialogue.

A similar reason to seek information was given by Mark when he explained how he found out about stroke services in his area.

> There was a stroke magazine, a local magazine that went out that I saw a copy of when I was in the stroke unit, it doesn't get published anymore, but

> that had details of [patient support] groups in it, and that was one of them, so that’s how I found about that group […]. You need to look for things to do because they are out there, I mean, lot of people just sit, and nobody bothers with you and, but I mean, I’ve found all of those things. – *Mark, M, 50s, neurological condition, multiple long-term conditions*

Just like Angela and Charlotte, Mark highlights how seeking information is important when “nobody bothers with you”, hence also drawing on a narrative of abandonment, or limited expectations about getting care. Like Charlotte and Jack, Mark thinks it is the person’s responsibility (“you need to look”) to react to such lack of help by taking the initiative. Mark also shows how the patient’s quest for information is varied as it is not necessarily about looking for information on the condition, but also about patient support groups or other services in the area.

Charlotte showed yet another reason to look for information independently and outside of the healthcare sector.

> I used to have restless legs, […] and I went to a doctor, and the doctor gave me these tablets […]. It just totally knocked me out, and I thought “I can’t take these”, and I went back to see another doctor, he said “you should never have been given these”, they were for people who had Parkinson’s, and […] they had lots of side effects, […] so I looked for myself […]. I got a booklet about restless legs, and it was people with different ideas about what could help them […]. Somebody recommended magnesium – and it worked! – *Charlotte, F, 70s, arthritis, multiple long-term conditions*

Differently than her previous episode, in this excerpt Charlotte’s narrative was not one of abandonment, but of doubt: Charlotte doubted the usefulness of the doctor’s prescription, as she got advice that did not work for her. She initially tackled her doubt by seeing another doctor, indicating that she expected her problem to be solved by healthcare professionals. Yet, she eventually looked for an answer (and found it) in a booklet written by other people with restless legs.

Charlotte’s ‘quest’ for information started as a personal and individual one (i.e., finding a way to deal with restless legs), yet found its destination in reference to others, and in the help she indirectly got from people with the same condition. Finally, this also highlights how Charlotte considered people’s experiential knowledge a valuable tool that can be applied to the management of their conditions.

In summary, information seeking in this dataset was characterised by the act of looking, the sense of abandonment, the experience of inconsistency and doubt, and the importance of experience-based learning.

However, seeking information was not the only way in which participants learned about their conditions. Sometimes, the participants also spoke about the need for learning through a process of experimentation. I talk about this in the next section, in which I introduce the sub-theme “experimenting”.

4.1.2 Experimenting

This sub-theme describes the participants’ tendency to experiment, which was particularly evident in their accounts of how they looked for better treatments (e.g., treatments with an acceptable balance between the condition’s symptoms, the medication’s side effects, and number of tablets to take). Several participants engaged in activities like changing medication types and doses and evaluating their effects. For example, Jane described how she identified the amount of medication that worked best for her.

> With the balance [issues], I’ve found that I was better on half the dose three times a day [rather] than the full dose I was given after a while, and so that’s better for me physically […]. And also medication for sickness, I have less of that. But it’s a trial thing. […] When it first started, I was hitting my head on the wall, cos [the pain] was horrible! […] The aspiration within that [process] is […] to have courage to just go for things, and ok, I might fall over but you get up again, [*smiles*] and that’s the thing, to not be afraid

> to fail or fall, because that’s how we learn. – *Jane, F, 70s, neurological conditions, multiple long-term conditions*

Jane’s account describes her experimental attitude as she talks about a trial-and-error process whereby she changed her medication dose until she felt like it worked for her. She describes a process of discovery that not only involved ‘experimenting’ with different doses, but also adapting to her pain. Jane’s trial and error activities required persistence and enduring some falls, and she went as far as to say that they required courage, because making mistakes (“fail or fall”) was for her a concrete and scary possibility. Still, what was initially scary for her eventually became an integral part of learning, indicating that she did indeed build confidence throughout the process.

Whereas Jane framed her practices as a constant trial and error exercise, experimenting with medication meant for Patty that her doctor might perceive she was “messing about”.

> The statin, I stopped taking that because it affects my back, and I can’t walk. But then, when I stop taking that, I get the angina attacks, so I have to start taking it, and the doctors would be horrified I’m just messing about [*smiles*]. – *Patty, F, 70s, respiratory condition, multiple long-term conditions*

Patty decided to use the statin to deal with symptoms, rather than to prevent symptoms (as it was originally intended by her GP). Although she did not express worry or anxiety over this practice, she acknowledged that she needed to make doctors aware of what she was doing. Although both Patty and Jane found experimenting with medication useful in their own ways, Patty frames her practice as something wrong, while Jane finds an “aspiration” within that. Still, throughout her interview, Jane made it very clear that she had always made her doctors aware of her choices and of her thoughts about medication; she said “[doctors] have helped with that, and allowed me to just tinker with [medication]", something that Patty said she never had the chance to do. Therefore, while experimenting with medication types and doses could be done independently, being in touch with the doctor about it was considered more helpful. This was further confirmed by Nora, who explained how data provided by her practice helped her understand how to manage her condition.

> I've got to watch my blood, hemoglobin and everything, you know, and so they, on my annual [review] or 6 months [review], they put the numbers in, and then they'll say: "Well, that's normal", and you can see what the norm, is, and I get this piece of paper so I can see where I'm going. Because […] if I'm going over I can do something about it. […] I think that's been a good thing for me, for my personal use – *FG2, Nora, F, 80s, endocrine condition, multiple long-term conditions*

In this example, Nora explains that the staff at her practice helped her understand her blood test results and gave her a document with reference ranges for her "personal use", which helped her keep the values in check in her own time, and then decide herself what to do when any such values were outside the range.

4.1.3 Reflection

Reflection was an activity that participants would sometimes incorporate in the management of their conditions, for example when it came to lifestyle choices and medication use. It transpired through some participants' tendency to ask themselves questions about the usefulness of their treatment, or to not take things for granted. For instance, during her interview, Mary described the moment in which she started wondering whether she really needed to take all the tablets she was prescribed.

> I was on a tablet called Ranitidine, […] and when I looked it up, it was to keep your stomach ok from the medication that you were taking, and I thought "Well, I'm only on these tablets, so why should I be on this one as well?" […]. When you look at your tablets, you've got to think "well, do I

> really need it?", cos I'm not one to take a medication if I don't have to. […] And I've asked [the doctors], and I've been able to come off them. – *Mary, F, 60s, kidney disease, multiple long-term conditions*

Mary talks about a duty to reflect on the usefulness of her treatment ("you've got to think"), which is manifest in a personal goal to reduce her medication. In this excerpt, she describes a reflexive process that prompted her to doubt about the usefulness of some of her medication. This process of reflection required an understanding that some tablets were to protect her stomach from the action of other tablets, and a realisation that she was not taking enough tablets to justify the use of a gastroprotective drug. Eventually, Mary being reflexive contributed to the management of her long-term condition, as once she knew what the medication was for, she decided to ask the doctor if she could stop taking it.

Similar to Mary, who believed that one "has" to engage in reflexive practices, Jane said that one has to be willing to embark on a complex journey if they want to learn how to manage their long-term conditions.

> If you're managing energy levels, […] and the practicals of every day, when you first start it's kind of awkward, and you have to be willing to go on that journey I think, to be inconvenienced, whether it's being in a bit more pain than you'd like but you're on less drugs, and see how that goes for a period of time, and sitting there, so, yeah… and if [too much] pain happens at the same time, well, what am I gonna do with that? – *Jane, F, 70s, neurological conditions, multiple long-term conditions*

In this excerpt, Jane described the process she went through to learn to cope with the pain caused by her condition, and with the side effects of her medication. She described a reflexive moment when she said "and sitting there", as in taking time to concentrate, to get in touch with her body, and evaluate how it is reacting to the medication or to her pain. Jane defined this journey as complex, inconvenient and uncomfortable (e.g., being "in a bit more pain than one would like"), but also indicates that such discomfort is part of what allows a person to reflect on their condition and find out what works best for them. For Jane, this journey is worth embarking on. Her words describe the evolution of such journey, which started as “awkward”, and did not bring her to a definitive solution, but rather to a compromise that worked for her (“now I can cope with a certain level”). This indicates that the journey’s worth in this case lies in the learning process, and thus in its value for the management of Jane’s condition, even if it does not lead to a complete resolution of the symptoms.

This idea of the “journey” with a long-term condition was mentioned explicitly by Jane, but intertwines with the experiences of other participants as well. Several participants used expressions like “keep going” (Thomas, Ann and Patty) or “getting somewhere” (Julia) in the context of learning how to manage their long-term conditions, or of communicating with health professionals about its management. They could be motivated by different goals, such as taking control over their illness, achieving better quality of life, or finding peace of mind. Their knowledge work unfolded through a journey of exploration that is exemplified in this section by Charlotte’s effort to find information about restless legs, Mary questioning the usefulness of her medication, or Jane’s constant reflection on how drugs affected her body. Instances of the participants’ reflexive quest for knowledge hence became a meaningful part of their learning journey, and towards supporting their own health. As Jane and Mary demonstrated, the reflexive learning process was not a casual or random occurrence, but rather a deliberate and conscientious effort.

This section has therefore outlined how participants described their knowledge work as a continuing learning journey which enabled them to acquire more knowledge and understanding about their conditions (including their management) through a combination of information seeking, experimentation and reflection. In the next section, I describe the knowledge gained through these processes in more detail, and explain why the participants found it relevant not only to their own circumstances, but also in the context of clinical encounters.

4.2 The participants’ acquired experiential knowledge

In the previous section, I have described how the participants engaged in self-learning through a “journey of exploration” characterised by activities of information seeking, experimenting, and reflection. Some of them described experimenting with their medication doses and types under the supervision of their doctors, whereas others did it independently. Reflexive practices contributed to this process and helped them identify issues or questions to bring up during the clinical encounter.

In this section, I describe the characteristics and value that participants attributed to their acquired experiential knowledge for clinical decision-making as they learned through these self-directed practices. Here, I use the word ‘knowledge’ to refer to the participants’ understanding of and familiarity with their condition.

The theme of the participants’ ‘acquired experiential knowledge’ is derived from the participants’ accounts of the ways in which they used their knowledge, and from the occasional comparison of such knowledge with that of the practitioners. In the next few paragraphs, I present the characteristics of the participants’ acquired experiential knowledge from their perspectives. I describe three sub-themes: the exclusivity of knowledge (the participants described a dimension of the illness that can be known only through its lived experience), its functionality (as this knowledge helped the participants interpret and understand their symptoms), and its uniqueness (as the participants expressed a personalised understanding of their conditions).

4.2.1 Exclusivity of knowledge

One of the characteristics of the participants’ knowledge from their perspective was its exclusivity, which describes how experiential knowledge could be accessed only by the person living the experience from which that knowledge comes from.

This was expressed by Ada as she was talking about the importance of being in touch with people with the same condition as hers.

> Sometimes we know about our illness more than anyone else at the practice, nobody knows what that illness does. […] Because we live it, so we know, and because we're living it, we know more about the illness than anybody, you know, probably Dr. [name] knows a little bit more than we do [*smiles*] – but then, he's a consultant, but when you're living something, it does help, especially if you're first diagnosed, it does help to have somebody [with the same condition as you]. – *Ada, F, 70s, respiratory condition*

Ada affirmed that living with a condition provides someone with exclusive insights, as only people with a long-term condition know "what that illness does" because they "live it", implying that there is a dimension of the person's illness that is accessible only through its lived experience, and perhaps invisible to everyone else, including the medical experts. Actually, in this excerpt Ada identifies two types of knowledge: the knowledge of consultants, and the knowledge of patients like her. Whereas patients know that some doctors might 'know more' than them in some respects, Ada also feels that they know more than the doctors in other respects, making such types of knowledge complementary. Ada also acknowledges their differences, as exemplified by the following quotes.

> It's quite nice to talk to people that are the same, because you know that they understand, and if you're newly diagnosed you can hear someone […]. I know that if I mash anything my heart rate goes down, so I know I have to take [a break]. So, it's [about] explaining to people really, the newly diagnosed, that you can live with it, you just have to manage your time, space yourself out. – *Ada, F, 70s, respiratory condition*

> I’ve had [a respiratory condition], I’ve had a pulmonary embolism, so [it] bothers me a little bit that [I won’t] see a consultant [anymore]. […] When you’re doing the medical trials you get quite good treatment, so that’s the only reason it bothers me, that I will lose it at the end of the year. […] I just find if you’ve got a consultant there you just feel a little bit safer than if you don’t. – *Ada, F, 70s, respiratory condition*

The previous excerpts clarify that, for Ada, patients and consultants contribute differently to the patient’s health; the patient by giving advice about how to manage a long-term condition, and the consultant by providing good treatment and access to medical trials. Although Ada compares the knowledge of patients with that of the consultant (‘knows more’), she does not say that they are competing views. Rather, she finds particular value in learning from other patients that she does not get from her consultant. The experiential knowledge of people with the same condition helps newly diagnosed patients adapt to a new lifestyle with helpful advice. When she talks about the consultant, she uses more medical terms (“pulmonary embolism”, “medical trials”, “treatment”), indicating that the consultant’s contribution from her perspective mainly lies in the medical sphere, and in a feeling of reassurance that comes from the “good treatment” that the consultant helps her access.

Oliver also compared his doctor’s knowledge with his own while he was telling me about a time in which his doctor decided not to prescribe him the antibiotics he was asking for. He then used a joke to emphasise the value of his experiential knowledge.

> [My GP] has read fleeting passages about [my condition], whereas I’ve had it for twenty years, I’ve got twenty years’ experience! [*laughs*] – *Oliver, M, 60s, respiratory condition, multiple long-term conditions.*

In this example, Oliver compares his experiential knowledge (“I’ve had it for twenty years”), with the doctor’s knowledge, that Oliver believed was mainly acquired through studying and reading. The exclusivity of experiential knowledge comes into play when Oliver explains that he was the one person that could know what was best for him, because he was the one living with that condition. He added that he had “twenty years’ experience” with his condition, using the same language that people use to describe work experience. For Oliver, the time spent with his condition and his personal experience with certain antibiotics made his insights exclusive and therefore valuable from a clinical perspective and, in this instance, more valuable to him than the doctor’s clinical knowledge.

4.2.2 Functionality of knowledge

Through experience and the exploratory process described earlier, the participants also reported gaining functional knowledge, namely knowledge that they could apply to a problem. For example, this knowledge could help them identify the occasional mistakes made by healthcare professionals.

> Julia: Errors do occur.
>
> Lucy: Well, they do, [at this place they] gave me double hydrocortisone, and they said I should have put a complaint, I said: “Forget it, you all make mistakes, it’s absolutely fine”.
>
> Julia: Yes, you do, but – you see, you could have taken it without realizing it. You know you’re on the board because you take regular medication and you know how it is, but if you’re elderly or you’ve got any form of dementia starting, you might not be aware. – *FG3, Lucy, F, 70s, endocrine condition, multiple long-term conditions; Julia, F, 60s, respiratory condition*

In this case, Lucy did not only describe how her knowledge helped her spot a mistake, but also showed how confident she was in her knowledge, as she did not want to raise a complaint because she was not worried about the health professional’s mistake, which she could easily identify through her experience taking regular medication.

Other participants believed that their experiential knowledge was clinically valuable because it allowed them to understand when something was wrong with their bodies. Ann, for instance, said that she knows when she has a chest infection.

> Ann: I had an infection, and I knew I did, <u>I know</u> when I have an infection.
> I: How do you know?
> Ann: How do I know? I start being not very well, I start crying more, it sounds really silly things [*smiles*], my legs go from under me [sic], hum, I'm weak, I'm incontinent. – *Ann, F, 60s, respiratory condition, multiple long-term conditions*

Whereas Ann provides an accurate description of her feelings when she has a chest infection, Emma felt she lacked the ability to 'know' with certainty, and said it is hard for someone to know when they have an underlying infection.

> If you got an infection, which is probably the hardest one to know – 'cos' you know when you're being sick, you know when you've broken your ankle, but if you've got an underlying infection, then I think that's quite hard, because you, if you got a fever then it's obvious, but if it's just something kind of bubbling under, then – maybe a virus or something, you're not quite as aware of it. – *Emma, F, 50s, endocrine condition*

Still, experiential knowledge differences explain the contrasting perceptions of Emma and Ann. Whereas Ann had a pulmonary condition, Emma had an endocrine condition. Ann had been long alert to (and experienced) pulmonary symptoms and felt confident about detecting a chest infection, while Emma was not, as she did not commonly experience chest infections. Actually, Emma also said she was able to know when her cortisol levels were going down and, just like Ann, she was able to provide a description of her symptoms when it happened.

> I'm very used to knowing when my cortisol levels drop, I think the nurses said to me that I'm quite sensitive to it, because I am, and if I've forgotten a tablet, […] and it's maybe been an hour let's say, I do genuinely start to feel something, and I can't quite – it's not a headache, it's just some sort of strange feeling. […] Sometimes, if I'm really busy at work and I've forgotten it, I start being really clumsy, so I trip a bit, or I might drop things, and then I think "Why am I doing that? Oh, yeah", and then I take the tablet. *– Emma, F, 50s, endocrine condition*

In the excerpt above, Emma invokes the nurses' medical knowledge to validate her own, though she also personally believes that she is sensitive to her cortisol levels, as she immediately adds "because I am". Emma was confident about feeling her cortisol levels going up or down, because that was what she had experience with, and also reflected on. Therefore, although Ann's and Emma's statements about "knowing" and interpreting their symptoms may look different at a first glance, their stances are actually not that far from each other.

A different perspective was offered by Jane, who learned not to listen to her own body all the time, because it can be deceiving.

> I'm very much in tune with my own body, and what works and what doesn't […]. [With my] balance [issues], my eyes move about a bit, so things move, hum, the ground moves, so with the cane, […] if it's on the floor, I know the floor's not moving, but my brain may be telling me [that it is]. So […] I don't listen to my brain, I listen to the cane [*laughs*]! So, it's listening to your body, but also being free enough to maybe not listen to it and listen to something that is absolutely being helpful. So it can work both ways. *– Jane, F, 60s, neurological conditions, multiple long-term conditions*

Jane acknowledges that one's brain can deceive, but also implies that one can learn to identify such deceit. However, the challenge in this process is exemplified by the need of a cane, a tool that acted as a connection between Jane's body and the surrounding environment. This cane created for her a reference point, namely something she could use to understand when her mind was giving her deceiving signals. Therefore, the functionality of the participants' acquired experiential knowledge does not only refer to knowing how to listen to one own's body, but also when not to listen to it.

For the participants, confidence in their interpretation of their symptoms was built over time as they gained more experience with them. This was explained by Lucy, who said that she learned to listen to her body after many years on medication.

> Since I've been on medication for twenty years, I know now if I'm not well […] or if I've got a flu or something, I know how to adjust it now, because I'm so used to my body to lead, really. [Now] I feel in control of it. – *FG3, Lucy, F, 70s, endocrine condition, multiple long-term conditions*

According to Lucy, the consolidation of her functional knowledge occurred over a long period of time. In her account, her acquired experiential knowledge was functional not only because it helped her learn to understand her symptoms and the side effects of her medication, but also because it allowed her to be in control of her condition. Other participants also indicated that this was built over time, after their initial idea had been confirmed (or not) enough times (by doctors or by diagnoses) to increase their confidence in their own understanding. For example, they would compare similar symptoms, like Matt did.

> Last time I went [to the GP, I saw] a young girl. I started telling her, I said "I've got arthritis in me arm". [She asked me] "How do you know?", [I replied] "Cos I've got it in my leg, and I'm having the same symptoms". I'll tell her, she sees the computer, [and then she says] "I don't think it is [arthritis], I think it's a reaction". […] But it's the same [symptoms] that I've got in me bloody leg! – *FG4, Matt, 60s, multiple long-term conditions*

Like Jane in the previous example, Matt had his own reference point for understanding what was wrong with him, as he compared the symptoms in his arm to those that he previously experienced in his legs. He thought they felt the same, he believed that they were due to the same health issue (arthritis). Therefore, comparing symptoms was a way for Matt to aid his interpretation of what was happening to him.

4.2.3 Uniqueness of knowledge

Whilst the participants in this study described the knowledge they acquired through experience as exclusive to the patient perspective (compared with professionals/people without the condition), and as functional (as it could be applied to a variety of problems), a third sub-theme that describes the participants' acquired experiential knowledge is 'uniqueness'. Unique knowledge means personal and personalised, and thus unique to 'my' specific experience of a situation. For example, some participants said that people with similar conditions often experience them in different ways, hence knowledge of their specific circumstances was crucial to properly inform their care. Eva, for example, said that she realised that her respiratory condition does not affect everyone in the same way. Martha, similarly, talked about her muscles' problem as her own, individual problem.

> I'd just been diagnosed, and I thought […] "oh, my God, is this what it's going to be like?", until [I started] going to the [patient support] group, and I realised that, you know, people are different, and have different levels [of illness]. – *Eva, F, 70s, respiratory condition*

> The main problem is that those muscles here [*points at her quadriceps*] were the ones I had to use instead of the knee muscles, and so that's my individual one, and so I don't like the idea of giving advice […] because the way [people's] metabolism is, is different from everybody. – *Martha, F, 70s, heart disease, multiple long-term conditions*

Eva realised that a condition might manifest itself in many ways once she joined a support group for people with respiratory conditions. Martha said that she had her own problem, which affected her in its own way. Other participants similarly expressed understanding the *uniqueness* of their illness. This common observation was not inherently positive or negative. In Eva's case, it gave her hope that her condition might not affect her as badly as she initially thought. For Martha, it meant that she could not give advice to people with the same condition, and that they might not be treated in the same way as her, because there are also other things to consider (e.g., their metabolism). Whereas these remarks indicate that people are different, and each situation has its peculiarities, they also indicate that people with a long-term condition can contribute unique insights to the clinical encounters, defined by the uniqueness of their circumstances.

Summary – Chapter 4

In this chapter, I have described the participants' learning journey. This journey was made of activities of information seeking and experimenting, guided by moments of reflection, and resulted in the participants developing experiential knowledge that was exclusive, functional, and unique. Their experiential knowledge was exclusive when compared to medical knowledge, as it could only be accessed by the person living with the condition; it was functional, because it could be applied to the participants' health problems; finally, it was unique, as it was personalised and different for everyone. These themes and sub-themes are summarised in Figure 4.1.

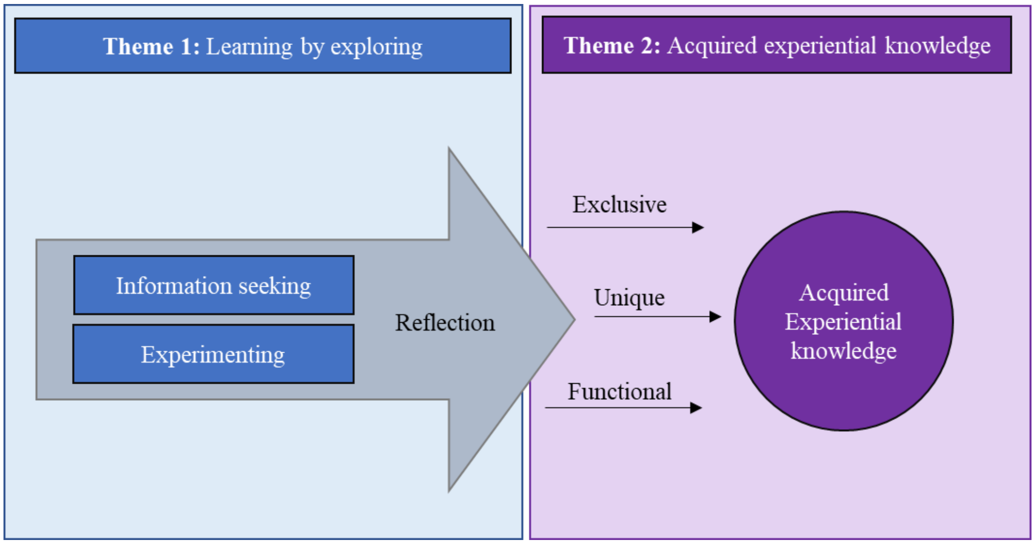

Figure 4.1. Themes 1 and 2: “Learning by exploring” and “Acquired experiential knowledge” and their sub-themes.

Whereas the participants wanted this knowledge to be integrated with the practitioners’ own insights during clinical encounters, their experiences describe that this was not always possible. In the next chapter, I describe how the participants tried to bring their knowledge into primary care settings. I start by introducing their perspectives on organisational restraints to knowledge exchange and on the conflicts with practitioners that occurred when they tried to share their knowledge. Then, I introduce the clinical negotiation with knowledge as a person-centred way to integrate doctor and patient knowledge during clinical consultations.

Chapter 5 – Bringing patient knowledge to primary care settings: A negotiation with knowledge

In Chapter 4, I described how the participants developed an understanding of their illness and its management through their experience of living with a long-term condition. They were confident about the relevance of their acquired experiential knowledge to a clinical consultation, and to discuss and negotiate an understanding of their illness and management plans.

In this chapter, I consider how bringing that acquired experiential knowledge into the clinical encounter creates challenges. Then, I consider how the participants use such knowledge to negotiate with health professionals an individually tailored understanding of their illness and its management.

5.1 Challenges to knowledge integration

I developed the theme “challenges to knowledge integration” in the context of the participants’ accounts of trying to bring their acquired experiential knowledge into primary care settings. It is characterised by two sub-themes: the first sub-theme, “organisational restraints to knowledge integration”, describes the organisational restraints on the clinical consultation identified by the participants, as they indicated that the healthcare system is organised in such a way that leaves scarce room for integration of patient’s knowledge into clinical settings. The second sub-theme, “conflicts arising from competing types of knowledge”, explains how challenges to knowledge integration could be due to a conflict arising from competing or contradicting perspectives. These sub-themes are summarised in Figure 5.1.

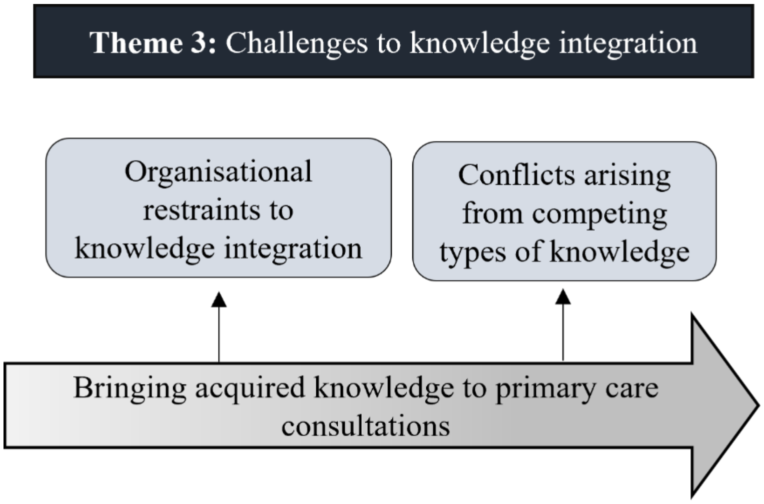

Figure 5.1. Theme 3: Challenges to knowledge integration.

5.1.1 Organisational restraints to knowledge integration

The experiential accounts of the interview participants indicated that the practice's policy itself could undermine the doctors' capacity for care delivery, with consequences for the participants as well. In Ada's example, the time-limited appointments in her practice led her to withhold information from the doctor.

> There is a ten minute time slot for each patient, and I think some patients need a lot more than ten minutes, and when you, if you're aware that there's a ten minute time slot, and you're aware that you are over it, maybe you're into fifteen minutes, twenty minutes, you almost feel guilty, and – you know, perhaps you don't share as much as you perhaps would be, it's that pressure time, there's no doubt about it. […] Nowadays, you're so much more aware that there is an allotted time space for your appointment. – *Ada, F, 70s, respiratory condition*

In the above excerpt, Ada's own feelings of guilt for going over the allotted time led her to share less information with the doctor. In this case, the doctor's attitude was not responsible for the potential loss of information, as Ada recognises the doctor's willingness to give her more time than allowed. Still, Ada implies it might have been in vain. Her perception is that there is not enough room for information exchange, so the patient's needs are not met. On the one hand, whereas Ada as a patient wants to tell a story, her doctor has a task to complete, and does not necessarily need all the information that Ada can give. On the other hand, there is a challenge for both of them when the context prevents Ada from sharing something that does matter, and that her doctor would like to know.

Others also recognized organisational priorities as impacting on the processes of knowledge integration. Focus groups participants reflected on similar concerns but framed the problem specifically in terms of service priorities. Jack and others described the NHS as a business that is primarily concerned with money and resources, rather than being a service primarily concerned with patients.

> I think the whole thing is, from my perspective, [the NHS] is geared for what they're doing, not for you as a patient. […] Because of financial constraints, and people not available, companies are taking over individual surgeries because it's financially viable for them, but it's working for the organisations and not for individual patients. – *FG1, Jack, M, 70s, endocrine condition*

> Samuel: I just wanna say something now, you know, the NHS is what it is, they should take the business out of it, shove the business to one side, and make the service.
> Erin: Too many managers and not enough doctors I would say. – *FG3, Samuel, M, 60s, multiple long-term conditions; Erin, F, 60s, endocrine condition, multiple long-term conditions*

In the first excerpt, Jack blames companies and financial constraints for the shortcomings of care. His account hints at a distance between him as an individual patient, and the organisations that follow their own interests. However, he is not including health professionals in his reflection. Similarly, Samuel and Erin perceive a business side of the NHS, which is in contrast with the care side (service and doctors), and even ends up overshadowing it.

Whereas some participants saw doctors and health professionals as part of the organisational issues they were dealing with, others saw them as victims of the system, which limited their capacity to practise effectively. These participants specifically talked about conflicted professionals, who had to deal with a great amount of work before they could help them. This was explained by Nora when she was thinking about the paperwork that her doctor must complete before referring a patient to a specialist.

> I found the doctors can't just refer you to a specialist. They have to go through a long list of about 57 questions, before they can […]. And it's more and more paperwork, you know, and you just got in a vicious circle sometimes, you get referred for one thing, and then something else happens, and it's the same thing, but you can't go back again, go through it again, you know… That is the government, they've got all these clauses. – *FG2, Nora, F, 80s, endocrine condition, multiple long-term conditions*

Nora was empathetic with her doctor because she knew what her doctor had to go through in order to refer her or other patients to specialist services. In Nora's story, this awareness helped her forge a mutual understanding leading her to see her doctor as a victim of the system, just like her, and an ally for navigating the system together. In Nora's account, institutional restraints become a third party in the clinical encounter. Actually, in the type of care described by the participants in this section, multiple stakeholders intrude in the care process. Examples of these stakeholders from the participants' perspective were the government, the pharmaceutical industry, or private companies. In this context, the participants were brought to make sense of their healthcare experiences as based on the exchange of services and resources (e.g., if doctors answer to 57 questions, they get to refer the patient in exchange). However, they also indicated that this was not an ideal way of delivering care. As Ada and Nora explained, interactions based on such processes did not accommodate for the complexity of chronic conditions and were even responsible for creating vicious circles instead.

To summarise, the participants described several organisational limitations that they believed could affect the integration of knowledge during the clinical consultation. These included challenges of time available, organisational priorities, and conflicted professionals.

In the next section, I describe situations in which practitioners were seen as hindering the process of integrating knowledge during clinical consultations. In these cases, the participants described conflicts with their doctors caused by competing types of knowledge and perspectives.

5.1.2 Conflicts arising from competing knowledge

There were several examples of conflicts arising when different types of knowledge were introduced or used by the participants or their doctors during the clinical consultation. For instance, in some cases, metaphors of power were used by the participants in the context of being prevented from negotiating knowledge. This can be seen in Julia's account, as she described having to see a doctor for ten months before he agreed to refer her to a specialist.

> Julia: At my previous surgery I went for ten months, I kept saying "I need to have my medication changed and I need this and this", [the GP said] "we will try something else", [I replied] "[but] this is what I need", and they said "no, we'll try this [instead]".
> I: Why would they say no?
> A: I presume it was expense. So, in the end I said "I want to be referred". [The GP replied] "Try another month". And I lost my rag, and I said "I want to be referred now!" So he sat there, spinning in his chair, […] "yeah, ok, then I'll agree to refer you on". […] I was enraged! […] So I […] saw this consultant, lovely lady, who took one look at me and said "well, you shouldn't be on this medication" and I said "thank you! Thank you!" Now I'm getting somewhere, and I've been on this medication for a few years now, and my life has turned around. – *FG3, Julia, F, 60s, respiratory condition*

Julia believed that she needed a specific drug, and expected her GP to recognise her knowledge and prescribe her such medication (like the specialist did). When Julia realised that the negotiation with her GP would not get her what she wanted, she asked for a referral, to which her doctor agreed. However, at that point, Julia had already "lost her rag". From her perspective, Julia had been compromising by going to the GP and trying different solutions for ten months, but she did not see her doctor doing the same.

However, Julia's account also revealed her perception of a power dynamic when she described her doctor as he was "spinning in his chair" while deciding whether to help her or not. On the other hand, the specialist only took "one look" at her, immediately recognising the problem that Julia already knew about. Julia used the expression "took one look" to emphasise the GP's fault while validating her apparent knowledge (i.e., according to Julia, her 'truth' was so evident that it should take one look to see it, while her GP took ten months and still did not see it). The specialist's decision to prescribe Julia the drug that she was looking for further validated Julia's knowledge, as she also specified that her life has turned around after getting that medication. However, later during her interview, Julia said that she decided to leave that practice, indicating that the clinical consultations had a pivotal role in her decision to leave. Although she eventually got what she was asking for, the long and frustrating process made her decide to leave the practice anyway.

Whereas conflict in Julia's story was part of a narrative of power associated with frustration and vindication, Oliver's account of him asking for a specific type of antibiotics emphasises the actual process of trying to assert his experiential knowledge to guide decisions, though without success.

> They wanted to give me antibiotics which don't have much effect on me at all, "I would rather have that one, can you give me something else?", and the one they gave me, every time now, […] just won't affect me at all, whereas the one I'm taking now I'm moving in three days, I'm improving, which proves I've got the right one. And this [GP] says "no, I'm giving you this", […] and I'll say "well, I'll be back in a fortnight", and I was back in

> a fortnight just as bad as I was earlier. And [then] he [gave me the antibiotics I asked for initially], and that was it, that sorted it. – *Oliver, M, 60s, respiratory condition, multiple long-term conditions*

According to the extract above, Oliver knew from experience that some antibiotics would not help him. During the clinical consultation, he shared that knowledge as a way to get more suitable antibiotics. In § 4.2.1 (page 107), Oliver talks about a type of knowledge that was accessible only to him. Still, we can see from this example that this knowledge was competing with that of his doctor. At this point, a power dynamic is visible through the way in which Oliver remembers his GP's words ("no, I'm giving you this"), and in his apparent acceptance of the GP's decision while actually exercising his own power by saying "I'll be back in a fortnight". Also, as shown in § 4.2.1, Oliver further diminished the doctor's power by associating their knowledge to reading "fleeting passages" about his condition, and (just like Julia did) he gave power to his own experiential knowledge by saying that he was proven right eventually.

Whereas positional power dynamics (e.g., doctors' denying prescriptions or patients coming back until they got something out of the consultation) could affect the outcome of a consultation, they did not necessarily affect all conflicts of knowledge. For example, some participants almost showed reverence towards health professionals' knowledge. In these cases, it was the perceived power of the professionals' expertise that led the participants to doubt their own. This happened to Martha when the pharmacist convinced her to take medication though she was not sure about it.

> I saw one pharmacist with my condition, and he was wrong, […] but he was confident, [*laughs*] and so I ended up in the emergency thing, a week later. Because he was, assured me that it was the easy condition to treat, and I kind of knew it wasn't, but… he was, and I did take his advice, and so I went on holiday and it came quite poorly with this situation, so that wasn't good. – *Martha, F, 70s, heart disease, multiple long-term conditions*

In the previous excerpt, Martha does not describe a power dynamic as Oliver did, as she did not frame the pharmacist's suggestion as prescriptive, but as advice. However, the pharmacist's confidence in his knowledge persuaded Martha to doubt her own. Whereas Oliver in the previous example accepted the doctor's decision though he thought he was right instead, Martha "kind of" knew she was right, and listened to the pharmacist's advice as she was persuaded by his confidence, indicating that these negotiations could be more than moments of power play and information exchange; they were moments in which the participants' could reassess the value of their own (or the doctor's) knowledge.

To summarise, the theme of challenges to knowledge integration has two key components (sub-themes): organisational constraints and conflicts of competing types of knowledge. Organisational constraints were usually linked to time, prioritisation, and conflicted professionals' issues, while interpersonal conflicts over knowledge occurred because of positional or expertise power dynamics.

Specifically, the participants reported conflicts with practitioners upon the value and use of knowledge to guide clinical decision-making. These experiences, which include examples of being ignored, or of getting it right when the doctor got it wrong, can be interpreted as stories of conflicting types of knowledge. Patients and doctors also showed to have and exercise their respective powers associated with that knowledge: a doctor could decide to provide or restrict treatment based on their knowledge of medical guidelines, and a patient could decide to change practice, book another visit or not comply with the doctor's advice based on their lived experience with the condition.

However, the participants also offered experiential accounts of conflicting types of knowledge entering a reciprocal negotiation in a successful way. This happened through negotiation processes that managed to bring together patient and professional stories. I talk more about this negotiation, and about the integration of different types of knowledge in the next section.

5.2 The clinical negotiation with knowledge

In the second part of this chapter, I present the theme of 'the clinical negotiation with knowledge', which describes the process of negotiating knowledge identified by my analysis. This negotiation occurs through four types of moments (sub-themes): active exploration, amplified listening, and reciprocal inquiry (figure 5.2). I talk about each sub-theme in more detail in the next sections.

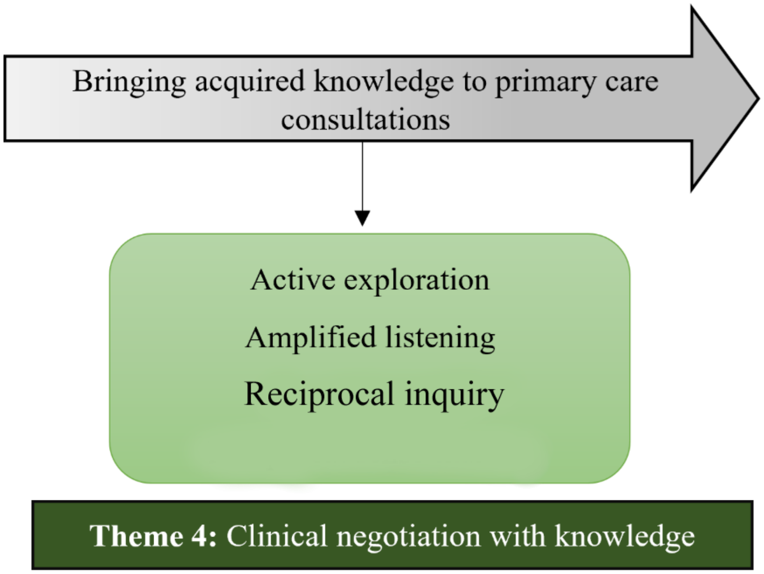

Figure 5.2. Theme 4: the clinical negotiation with knowledge.

Whereas the participants' attempts to bring their acquired experiential knowledge into primary care consultations could result in conflict in their experiences (as reported in section 5.1.2), their idea of clinical consultations resembled more that of a constructive negotiation. For example, during a focus group exercise in which the participants pretended to be a GP handling a complex clinical case (see appendix G to read the vignette on page 275), they said they would conduct the clinical consultation with the aim to reach a compromise. This meant weighting up different arguments, suggesting trying out a treatment for a short period of time, making sure the patient is properly informed, and offering a follow-up appointment to talk about how the treatment is going.

> I think it needs a bit of spin on it to explain to [the patient] that she could have a serious heart problem, and to try the tablets, just to try them out and see how it goes, you know. To try it out, to see how it goes, maybe come back and see in a week and tell us how she's doing. – *FG2, Daniel, M, 60s, multiple long-term conditions*

Explaining, promoting their own argument, and questioning the patient were some of the negotiation techniques that the participants proposed during the exercise. This shed light on how the participants understood the doctors' role as that of a negotiator, and that of the consultation as a respectful and constructive negotiation in which knowledge is shared by both parties.

Several participants in the individual interviews also described experiential accounts of successful clinical negotiations. Analysing such accounts led me to identify the actual moments during the consultation that guided doctor-patient negotiations with knowledge. These moments are (1) active exploration, (2) amplified listening, (3) and reciprocal inquiry. I describe them more in detail in the next sections.

5.2.1 Active exploration

I developed this sub-theme starting from the analysis of the participants' accounts of those moments in which their doctors asked them about their circumstances and/or their condition. This sub-theme represents one of the moments of the clinical negotiation with knowledge and explains how such negotiation was guided by the patient's and the doctor's attitude of "active exploration", namely openness to multiple possibilities as opposed to narrow assumptions about their problem.

One of the aspects that characterised active exploration lay in the doctor's and patient's communication style, for example the doctor's tendency to ask general questions and let the patient reciprocate. This was described by Jack while he explained why he liked his GP.

> Well, the GP has just retired, he was really good, first thing he would do, he would say "How are you this morning?" […] When I walk into your surgery, I want to say, "Good morning, how are you?" and you reciprocate that, you want to know about me, why I'm there for, how am I doing, […] now <u>that's</u> looking after me. – *FG1, Jack, M, 70s, metabolic condition*

In the above extract, Jack described his ideal start of a consultation. While he was describing his idea of a positive approach to the doctor-patient communication, he used the expression "want to know", which indicates that the doctor's questions should come from a position of genuine interest, in the sense that it seems to come not from the professional (role) but from the person. The doctor's general questions about how Jack is doing were an important part of this approach, as the doctor's knowledge of such circumstances made him feel looked after.

Emma's story contributed further insights into doctors' different inquiring attitudes, as she had two contrasting experiences in this respect. When she started being sick, and did not know why, she was seeing two doctors at her practice.

> I was very ill, before diagnosis, and I kept going back, and the woman, the female doctor that I had there, […] [pushed] for me to have an endocrine appointment, and the other doctor in the surgery […] thought "I'll give her another month or so, and have another blood test" […]. [The female doctor] kind of persevered instead of just thinking "oh well, it might be a viral problem" … you know, the blood tests weren't conclusive, but she could see that I was like, totally exhausted and I was quite gone as well, my face was thin and I had varied symptoms. – *Emma, F, 50s, endocrine condition*

Emma's experience in this case provides an example of the difference between a focused inquiry and a broader one (i.e., which takes into account multiple types of information). On the one hand, one doctor was narrowing his focus to one specific set of data, namely the blood tests results, which were inconclusive (hence the decision to repeat them). The other doctor, on the other hand, did not focus solely on Emma's blood test results, but also on her exhaustion, thin face, and Emma being "quite gone" (hence the decision to refer her to an endocrinologist). The extract above is an example of how taking into account different types of information took Emma's doctor beyond the specific information produced by one type of data (e.g., blood tests), and allowed her to "see", as Emma said, a different pathway which led to referral to a specialist.

Emma's case highlighted the importance of considering multiple types of information when it comes to the diagnosis of a health problem, though other participants emphasised this approach is important throughout the management of a long-term condition. This is because there are several issues contributing to the patient's illness experience, and some lay beyond the condition itself. Laura and Eva were among the participants who mentioned this. Whereas Laura was trying to define person-centred care during the focus group interview, Eva was complaining about the limitation of being able to raise only one health concern per consultation.

> I think, with person-centred care, it's not what you go to the doctors with, it's everything else. So, you know, you're not the knee replacement, or the heart transplant, or… there is the rest of you, I think it gets forgotten. – *FG2, Laura, F, 60s, multiple long-term conditions*
>
> When you go to the doctor, it's not just about your COPD, the COPD causes other problems as well. […] I was sleeping too much, and me ankles are swelling as well, so by the time I've gone to the doctors I've got an accumulation of things to ask him about. – *Eva, F, 70s, respiratory condition*

In the first extract, Laura describes person-centred care as an approach in which the condition does not overshadow the person, and the practitioner takes into account the person as a whole instead. Laura also said that the "rest" gets "forgotten", as if it is not considered by the practitioner. This is then reflected by Eva's experiential account, which adds another dimension to this sub-theme – namely, that of the co-existence of multiple health problems – and, in her case, the issue that her respiratory condition causes other problems as well. Eva needs multiple related issues to be addressed during the consultation, which implies that doctors need to be aware of them. In Eva's story, she also shows that active exploration is an activity that patients engage in, when they make sense of their multiple health problems and of the ways in which they affect each other, and construct a story for the doctor by taking all these elements into account ("an accumulation of things to ask him about").

To summarise, the active exploration sub-theme describes how both practitioner and patient go about exploring different types of related information during the clinical consultation. For practitioners, active exploration needed openness to multiple possibilities, being interested in ‘me’ (the whole person), and willingness for exploration of breadth through open questions. The participants also engaged in this explorative work, by reciprocating the doctor’s interest, and by making sense of how several health and related problems were affecting them so that they could communicate that to the doctor. However, some were prevented from doing so by those practices that allowed only for the discussion of one issue at a time.

Still, the possibility to talk and elaborate on their various health problems and circumstances was important to the participants, because it also allowed them to engage in more reflexive knowledge work as they talked, as I explain in the next section.

5.2.2 Amplified listening

Whereas active exploration was a way to facilitate the sharing of relevant information, listening to this information was another important moment of the clinical negotiation with knowledge. I developed the sub-theme ‘amplified listening’ in the context of the analysis of the experiences that the participants had with the practitioner’s listening attitude, and of their reactions to such experiences. This sub-theme describes the moment of listening as well as the participants’ reflections on their own accounts, which was allowed by a comfortable atmosphere.

Firstly, several participants clarified that what mattered for listening was not always the length of the consultation, but also its quality. This was discussed by both Kyle and William, who described positive healthcare experiences with doctors who listened to them, regardless of how much time they spent during the consultation.

> Well, I’ve never ever felt rushed, they’re always taking their time, listen to what I have to say, deal with me properly, and so I’ve never seen a GP looking at his watch. He takes as long as it takes; if it’s five minutes, that’s fine; if it’s twenty minutes, or twenty-five minutes, that’s still fine. – *Kyle, M, 70s, heart condition*

> I’m usually in there for about ten minutes, he just sits down, he has a little chat with you as well, like how you are... […] Two minutes listening is more, well, it’s better than ten minutes when [the GP] is not listening and just gives you a prescription. – *William, M, 40s, neuromuscular condition, multiple long-term conditions*

These extracts help define this sub-theme as they clarify that the pivotal role of listening and of taking time was not necessarily related to the availability of time itself (i.e., the length of the consultation as established by the practice’s policy), but to the practitioner’s attitude as a listener. This was also echoed by Liam, a focus group participant that complained about feeling kicked out the practice when the consultation time was up.

> A patient now feels less personal than they used to, you’re allowed twelve minutes, I know sometimes the doctors would go over twelve and a half minutes, […] then [you] get kicked out, I know that’s stretching it a little bit far, because some of the doctors are a little bit more considerate, but it’s what’s being done, and that way patients start to feel if they’ve been pushed towards the back rather than the front. – FG2*, Liam, M, 70s, multiple long-term conditions*

In the above extract, Liam acknowledges that some doctors did give him more time occasionally, but only to be rushed out eventually. He also uses diminishing expressions, for instance when he says that sometimes doctors go over twelve “and a half” minutes, or when he acknowledges that some doctors are more considerate, but just “a little bit”. These expressions served to convey his feelings of disappointment, ultimately reinforced by his statement that the patient, or himself, feels at “the back” of care, even when he gets more time than normally allowed.

Therefore, the participants appreciated it when the practitioner made them feel like they had time to talk. For example, a few participants used the expression “*sit* and listen” [my emphasis] when talking about positive experiences of being listened to during clinical consultations. In this context, being listened to became more than a way to make the participants feel relieved, or help them feel comfortable enough to share relevant information. According to Jane, being listened to allowed for knowledge work in the form of reflection, as she explained during her interview while she was telling me why it is important to listen to patients.

> [Being listened to is important] because you can hear yourself […] so it comes back, and you see it, you just see flashes of a way forward. And so, to me, the journey has been by degrees with a long term [condition], and it’s like little flashes that add up, and add up, and add up, and add up, that just give you that… bring you to where you are now, so there’s no one thing – it’s always more things that bring you to this whole thing for me, so being listened to [does that], yes. – *Jane, F, 70s, neurological condition, multiple long-term conditions*

In the above extract, Jane said that the information one is sharing “comes back”, as in a reflexive exercise in which what is told to the doctor, and comes from the patient, also returns to the patient in the form of “flashes of a way forward”, hence giving a hint about how to proceed. Interestingly, terms like “almost” and “flashes” indicate that what comes back (which can be a realisation, an idea, a hunch, and so forth) is not always enough in itself, but needs to be integrated with other “little flashes”. According to Jane, these flashes could come in small bits through the journey with a long-term condition (they “add up”), but they’re also developed and built on during the clinical consultation, as the GP gives the patient time to talk. Therefore, later during her interview, Jane also said that her success managing her conditions was also due to her “having a say” and working with her GP rather than “at odds”.

In this regard, another perspective about the patient’s reflexive knowledge work prompted by the clinical consultation was offered by Ann towards the end of her interview. As I commented that (research) interviews can have a therapeutic effect, though they take time, she replied as follows.

> Yes, it does take time to get it into your brain, [and] to know what you’ve got as well. […] I think some doctors leave you too long and not tell you about [the condition], I think they say “go home and think about it” yeah, you’re going home thinking about it, but you need somebody there – to, you know… I’m a knowing person, I need to know […] tell me, do you know what I mean? Tell me what I’ve got, tell me about it, tell me […] I’ve got Google, […] but sometimes you need a doctor to tell you, and understand it, and know it. – *Ann, F, 60s, respiratory condition, multiple long-term conditions*

This extract highlights the importance of the doctor’s role in supporting the patient knowledge work when it comes to reflexive (i.e., “think about it”) and learning (“tell me about it”) activities. Ann went home to “think about” the condition, but she needed somebody “there”. With “there”, she did not necessarily mean physically at home, but in her reflexive moment, as she needed somebody with her as she was thinking and reflecting about her condition. In her account, Ann is also showing us the patient’s knowledge work of making sense of their own illness. Although she could easily access Google, she said that she still needed a competent doctor to discuss her condition with, namely someone to listen to her, but also someone to listen to. This example echoes Jane’s account in that the patient’s reflexive moment is best experienced together with the doctor, rather than on one’s own. However, it also highlights how the moment of listening does not belong to the doctor alone, but to the patient as well, who listens as well as being listened to.

To summarise, amplified listening was a crucial moment during the consultation, as it allowed the doctor to build a relationship with the patient, and the patient to actively reflect on their own words. The expression “amplified” listening comes from those moments in which the doctor listens to the patient, but the patient also listens to themselves, with their insights coming back in the form of reflection and/or awareness. The contribution of doctors throughout this process was important as being listened to by a clinician allowed for a particular type of self-reflection, focused on health and recovery, as shown in Ann’s case. As reflexive processes during the consultation helped patients make sense of their circumstances, like Jane explained, practitioners also engaged in these processes during the consultation. This reciprocal inquiry, which I describe in the next section, was not only grounded in patient’s reflection and amplified listening, but also in the doctor’s ability to integrate different types of knowledge.

5.2.3 Reciprocal inquiry

Analysis so far has revealed the work that patients do to make sense of their illness during the clinical consultation. However, the participants’ accounts indicated that doctors were also perceived as busy trying to make sense of the patient’s illness in the light of the clinical guidelines and of the professional knowledge that they already had. In this section, I present the sub-theme ‘reciprocal inquiry’, which considers how both patient and doctor work together, throughout the consultation, to integrate their perspectives in constructing a plan to move forward grounded in mutual understanding. For instance, as the patient talks and reflects, the practitioner also collects multiple pieces of information and integrates them with the knowledge s/he already has. As regards the doctor’s engagement in reciprocal inquiry, its main features were the integration of different types of knowledge and flexibility.

The integration of different types of knowledge as part of ‘compromising’ refers to the doctor’s ability to integrate different types of information, by identifying relevant information and applying it to a specific clinical situation. Whereas the ‘active exploration’ sub-theme (described in § 5.2.1) was about the elicitation of multiple types of information, the ‘reciprocal inquiry’ sub-theme starts with the practitioner’s actual consideration of such information. A difference between the two can be exemplified by Angela’s case, as she said that she was able to tell her doctor about her illness experience, but also felt like her doctor was not taking it into account.

> I don’t want to have to be going [to the doctor] and feel you’re just going, write your prescription, goodbye – I want somebody to listen to me, and respond to what I say. […] I’m telling the doctor I’m having a really bad time with [my sleep disorder], and they’re just getting it down, and then they say “ok, well, here’s another prescription”. – *Angela, F, 60s, sleep disorder, multiple long-term conditions*

In this passage, Angela describes a linear process (i.e., *just* “going → write your prescription → goodbye”); her illness experience (Angela’s “really bad time with insomnia”), however, does not find its own place in it. Although the doctor was listening to Angela’s story (they were “getting it down”), they were doing so by focusing on the condition (hence the prescription), leading her to believe that they had filtered out what she was saying about her illness experience. The word “just” also indicates that such linear process, ultimately leading to a new prescription, was not everything Angela hoped to get out of that clinical encounter; as she specified during her interview, she was looking for an investigation into what was causing her sleep disorder. Angela’s example also shows that, while doctors are busy integrating or listening to patients’ information, patients are also engaging in knowledge work that focuses on assessing how or whether that information about them is considered and integrated with clinical decision-making.

Whereas knowledge of the patient’s illness experience was considered an important part of the integration process, clinical knowledge was also acknowledged by the participants as important, for instance by those participants who believed that their doctors did not have enough knowledge of their condition. This was expressed by Thomas when he talked about a time he went to his GP to discuss the results of his scans. He said that his GP was relieved that Thomas did not have cancer, without knowing that Thomas' condition was progressive and not treatable.

> When I went to the local GP, he got the results back. He said – he said: "oh, luckily it's not cancer", hum, he sort of more or less dismissed it […] I guess [the doctor] just, he maybe just didn't know or they didn't know how to progress it from their point of view. […] I didn't really know what to feel to be honest, because I didn't know anything about it. – *Thomas, M, 60s, respiratory condition*

The previous excerpt illustrates the sub-theme of reciprocal inquiry by showing how integration of collected information could not be complete without proper clinical knowledge. According to Thomas, his doctor was "at a loss", and so was he, which shows how his own knowledge work was hindered by the impossibility to make sense of his health problem with his doctor. When Thomas found out that his condition was progressive, he deduced that his doctor had been dismissive because, as he said later during the interview, "cancers are treatable", whereas his condition was not.

So far, I have described one of the characteristics (i.e., knowledge integration) of the doctor's engagement in 'reciprocal inquiry', and showed how critical assessment of collected information could not be complete without proper clinical knowledge, as well as knowledge of the patient's own insights. However, it is important to note that integration of these different types of knowledge did not imply agreement between the doctor and patient. This was exemplified by Oliver, who said that his preferred doctor was the one who listened to him, even when they disagreed.

> She listens, hum, she seems to understand more than the… I think they… a male one seems to know a bit more than me, even though I'm the one with the illness, whereas she listens to what I've got to say, and then tells me I'm wrong, whereas they'll tell me I'm wrong before I've talked [*smiles*] you see what I mean? […] I think the others find it quite hard to understand me a bit more, because I'm a bit more complex than [other people with respiratory conditions]. – *Oliver, M, 60s, respiratory conditions, multiple long-term conditions*

Oliver said that his preferred doctor understands more than the others, because she listens to him. He also said that a doctor "seems" to know more than him, this expression indicating that Oliver is not convinced that that is actually true. Still, Oliver's account illustrates the sub-theme of reciprocal inquiry by highlighting how "listening to" does not equate to "agreeing with" from the patient's perspective. Listening, in Oliver's opinion, means to value and thus critically assess his insights. As his doctor occasionally told him that he was wrong, but only after listening to him, Oliver had grounds to believe that she took into account and assessed his insights as well as her own clinical knowledge.

Another aspect of the doctor's engagement in reciprocal inquiry was the practitioner's open and flexible attitude, for instance by coming to a conclusion that was not necessarily definitive, but still open to change. An example of flexibility was given by Victoria, who was recalling a time in which she wanted to come off some of her medication, and her GP allowed her to do so, but with a compromise.

> I said "I want to come off some of my meds, can I come off?", and then I named the ones I wanted to come off, and he said "yeah, if you feel your body is ready to come off, and you're ok, let's take you off", but he said "I want it as a backup for you to keep", […] well, it was two meds I wanted to come off, one was […] a drug for more the serious time, and it had a lot of side effects. Not that I was experiencing them, but I thought that I could have a tendency, and so I said "I really don't need a very expensive drug"

> – he said “ok, I’ll take you off then”, but he said “the other one, what I want you to do, is keep what you’ve got […] and then you’ve got a backup, just in case”. – *Victoria, F, 70s, respiratory condition, multiple long-term conditions*

In this example, the clinical negotiation started with a request from Victoria. Her GP did not accept the request immediately, but negotiated with her first. Firstly, he had a condition (i.e., that Victoria knew that her body was ready to come off that medication); then, he offered Victoria to meet halfway, by reaching a compromise: Victoria would stop taking one medication, but would still keep the other one. Therefore, the outcome of this consultation was a flexible plan in which Victoria got to keep a medication as backup. This plan did not only support her health, as Victoria felt her body was ready to come off that medication (but could still take it in case of an exacerbation of her condition), but also Victoria’s knowledge work, as it gave her the possibility to reflect on her body’s readiness to stop taking that medication, be responsible for her own care, and understand and decide when to take the backup medication.

Whereas Victoria’s case can be considered an example of flexibility in the context of a person-centred interaction, Eva experienced a lack of flexibility with a doctor that did not want to prescribe her emergency antibiotics.

> Eva: The [nurse] […] gave me a pack [of antibiotics and steroids] straight away, so I could take them just in case.
> I: Couldn’t the GP sort things out in the same way?
> Eva: We went to the [pulmonary] rehab group, [the nurse] wrote to the GP when I first went, and said I should have had a pack, and I went to the GP and I said “can I have a pack?”, and he says “no”, and when I got me prescription he got me steroids but no antibiotics, but it’s the antibiotics that you need, with the steroids to take afterwards […]. I was feeling really ill with the steroids, and I thought “I’ll just take the steroids”, and me ankle went [*shows swelling of ankles*]. – *Eva, F, 70s, respiratory condition*

In this case, a compromise would have been giving Eva emergency antibiotics (like her nurse did), with the promise that she would take them only if necessary. Whether prescribing emergency antibiotics was right or wrong from a clinical perspective, the nurse helping Eva get them in the past created an expectation that she could get them again. However, as Eva specified later, this doctor did not know her, which made it harder for them to reach a flexible compromise. Therefore, whereas flexibility supported the successful clinical negotiation with knowledge, Eva's experience showed that her doctor needed some guarantees, for instance that he could trust her judgement. In the participants' experiences, this was possible when the doctor knew the patient, or when a nurse was guaranteeing for the patient.

So far, I have described how reciprocal inquiry requires doctors to integrate different types of knowledge while applying them to the patient's specific circumstances, and flexibility in the conclusions of such integration. It shows that a successful clinical negotiation does not always result in a definitive "solution", but rather in a flexible plan to move forward, and entails some back-and-forth movement between different types of information, and between patient and doctor. Still, reciprocal inquiry also describes the patient's knowledge work during this process. This was characterised by making sense of the 'content' and of the 'process' of the consultation, and was fostered by the reciprocity of the patient's and doctor's interactions. I describe these aspects of reciprocal inquiry in the next paragraphs.

As regards the content of the clinical encounter, it refers to what was said during the consultation. Therefore, 'making sense of content' exemplifies how the participants used their knowledge work to develop an interpretation or an understanding of what was being said during the consultation. With this respect, two contrasting experiences were reported by William, who dealt with two different doctors about his chronic pain.

> [At my previous practice] the prescription was written out before I finished talking, before [the GP] even examined me. [My new GPs] actually listen to you, ask questions, ask follow-up question, and then they […] give you

> options, “do you want to...” – My big toe was really badly. […] I went to the doctor, and he said, “right, have you had gout?” [I replied:] “No”, [and he said:] “cos the options are, I can give you some anti-inflammatories to take the pain swollen down, see if it doesn’t come back or it doesn’t come back for a while, or we can give you a dose of medication that you will be on to ensure that it never comes back”. [I replied] “I don’t want to be on any more tablets, just give me some ibuprofen […] and we’ll take it up from there”. – *William, M, 40s, neuromuscular condition, multiple long-term conditions*

In this excerpt, William described his different experiences with his previous and current doctors. He noticed a difference between them in that the previous doctor would not inquire into his situation: according to William, this doctor would not wait for him to finish talking, hence not allowing him to engage in the exploration and reflection work described in § 5.2.1 and § 5.2.2, and leaving him only with a prescription. On the other hand, at his new practice, reciprocal inquiry becomes more evident as the doctor’s explanation was exhaustive and relevant to William: different treatments were explained to him, including how they would work, and possible outcomes. Furthermore, the doctor himself asked William what he wanted to do, hence inquiring into William’s goals. This process gave William the chance to understand and reflect on the implications of each therapeutic route, and to be involved in the development of his own treatment plan by making an informed decision which was compatible with his goal (i.e., not being on any more tablets).

Whereas the participants’ experiences showed how both patients and doctors interacted to understand each other’s goals and opinions, they also showed that they evaluated the negotiation process, for instance by assessing the thought process that led a doctor to a certain conclusion. Emily, for example, explained that what the GP told her was not credible enough for her to follow his advice. While suffering from a chest infection, she called her practice to ask for a nebuliser, namely a machine that can help people breathe by turning liquid medicine into a mist. However, she was told that she could not have one.

> [The GP] said “we do not give – let patients have nebulisers at home. If you need a [nebuliser], you need to be in hospital”. I said “no, I ain’t going in hospital”, so he said “well, I must warn you, if you don’t, you might die”. [...] Oh, it was horrible […]. The [nebuliser] would have just relieved my symptoms and helped me breathe a bit better. […] But [this GP] hadn’t even seen me […]
>
> I: If he had said that in a different way, would you have gone to the hospital?
>
> Emily: I would have maybe considered it, yeah, but when somebody’s telling me that... well, if I’m gonna die, I’m gonna die at home, you know?
>
> *– Emily, F, 60s, respiratory condition*

Emily believed that her own GP would have got in touch with a respiratory nurse and provided her with a nebuliser. The GP that called her, on the other hand, would not do that, and did not convince her to go to the hospital to use one, because Emily believed that his argument was not strong enough. On the one hand, this example highlights a conflict similar to the ones reported in section § 5.1.2 (“Conflicts arising from competing knowledge”). However, it also provides a detailed account of Emily’s knowledge work involved in assessing the doctor’s knowledge, and in concluding that their conclusions were not credible enough for her. On the one hand, she uses her own knowledge: she knew that a nebuliser could not heal her, but could only relieve her symptoms; therefore, if the GP was right, and she was about to die, a nebuliser would not have made a difference. On the other hand, she knew that the doctor had not visited her, as they only talked on the phone, hence making her believe that he did not have sufficient grounds for his conclusions. Furthermore, Emily did not like the doctor’s attitude (the way in which he conveyed his message), challenging the legitimacy of the GP’s warning as she conveyed it felt more like a threat (“I must warn you: if you don’t, you might die”) and felt horrible. Finally, for Emily, the doctor’s conclusions were not relevant to her personal goals (i.e., to die at home). This story therefore provides an example of how reciprocal inquiry involves making sense of the doctor’s thought process, then acting according to one own’s judgement. This is also confirmed by Emily's statement that she would have considered going to the hospital, had the doctor's explanation or attitude been different.

The importance of making sense of the doctor's thought process was mentioned also by Nora, a focus group participant, as a way to help patients check how appropriate or valid the doctor's conclusion was.

> Nora: I've found all the doctors do listen. Granted the specialists don't seem to. They already know, without been told how you feel. You know, they've already decided what they're gonna do when you go to see the specialist.
> Laura: That depends on the specialist.
> Nora: Yeah, obviously, yeah. But obviously, sometimes you don't know what made him come to that conclusion, sometimes you'd like to know what made him come to that conclusion. – *FG2, Nora, F, 80s, multiple long-term conditions*

Nora mentioned that she met specialists that "already decided" what needed to be done without listening to her or involving her. Because of this, she thought that the specialist's conclusion had not been integrated meaningfully with her own insights ("how you feel"), as she did not have the opportunity to share them. Nora's words further confirm the patient's active role and knowledge work during the consultation: as the doctor speaks, the patient is busy assessing the doctor's thought process, indicating that patients like Nora want to be able to validate that process themselves. She did not necessarily question the specialist's conclusions, but wanted to know how they could be reached without any knowledge of her own insights.

Nora's reflection thus emphasises the reciprocity of reciprocal inquiry. According to the participants' accounts, doctors were actively involved in reciprocal inquiry, ultimately leading both patient and doctor to make sense of knowledge and information together. This included managing a clinical negotiation in which the goals of care were doing the right thing medically (e.g., issuing – or not – prescriptions, referrals, tests) but also knowing and understanding patients' concerns, anxieties, and sense of control (for example, by letting a patient have emergency antibiotics). To achieve this, the doctors needed to gather clinical knowledge and insights from patients. Therefore, Angela's doctor (page 132) could not make sense of her illness experience, because she said that he was not listening to her words; Victoria's doctor in the same section asked her about her body's readiness to come off a certain medication before actually taking her off it; William's doctor (pages 136-137) wanted to know his opinion before deciding on a treatment plan. In these and other examples throughout this chapter, the participants clearly explained how their doctors were (or were not) engaging in reciprocal inquiry.

However, a key characteristic of reciprocal inquiry was that both patient and doctor engaged in such activities together. Lorna, for example, said that her husband was never asked if he smoked when he was hospitalised for breathing difficulties.

> Lorna: When they took him in, it was the three doctors arguing… three doctors actually came to see him and were arguing whether it was COPD, asthma, and all three of them came to the same conclusion he'd been a smoker. And he never ever had.
> Jack: But did they ask, "have you smoked?"
> Lorna: Well, one of the things… No.
> Jack: Exactly! And that would have cleared that up completely! […]
> Lorna: They just assumed he'd been smoking.
> Jack: If they go back to the room they would never notice if he was missing.
> – FG1, *Lorna, F, 70s, endocrine condition, multiple long-term conditions; Jack, M, 70s, endocrine condition*

In Lorna's story, the doctors were busy making sense of what happened to her husband, but they were doing so among each other, and without involving him. Therefore, in this example, there is no reciprocity between doctor and patient. According to Lorna, this led them to come to the wrong conclusion (i.e., that he was a smoker). According to what Jack said, however, this was not only about misdiagnosing or being wrong: it also meant that Lorna’s husband, the patient, was invisible. For Jack, not only was this man not involved in the process of inquiry, but the doctors would not even notice if he went missing, as if he was not a valuable part of the clinical investigation process.

To summarise, the sub-theme of reciprocal inquiry describes the doctors’ and participants’ efforts to work together to integrate their perspectives in constructing a plan to move forward grounded in mutual understanding. A key characteristic of such processes was its reciprocity, namely the mutual involvement of patient and doctor in the clinical negotiation, which could make the difference between feeling valued and respected as a person, and feeling neglected and not involved in the care process.

Reciprocal inquiry unfolded throughout the various moments of the consultation, indicating that it is an ongoing interactive process, in which mutual understanding develops in an iterative way, and through a back-and-forth movement between patient and doctor and between different moments of the clinical negotiation with knowledge.

Summary – Chapter 5

At the beginning of this chapter, I have presented the challenges to knowledge integration experienced by the participants when they brought their acquired experiential knowledge to primary care settings. These challenges were either organisational restraints to knowledge integration, or interpersonal conflicts arising from different types of knowledge.

On the one hand, organisational restraints to knowledge integration mainly referred to those practice’s arrangements that hindered both the participants and their doctors during clinical encounters. Examples of these were lack of time, organisational priorities, and conflicted professionals. On the other hand, conflicts arising from different types of knowledge were affected by positional and expertise power dynamics, and were often characterised by narratives of frustration, but also of vindication when the participants’ knowledge was eventually legitimised.

Then, I described the successful clinical negotiation with knowledge, which was characterised by moments of active exploration, amplified listening, and reciprocal inquiry. As these moments did not present themselves in a set order in the experiences of the participants, I have reported them in a non-linear way in figure 5.3.

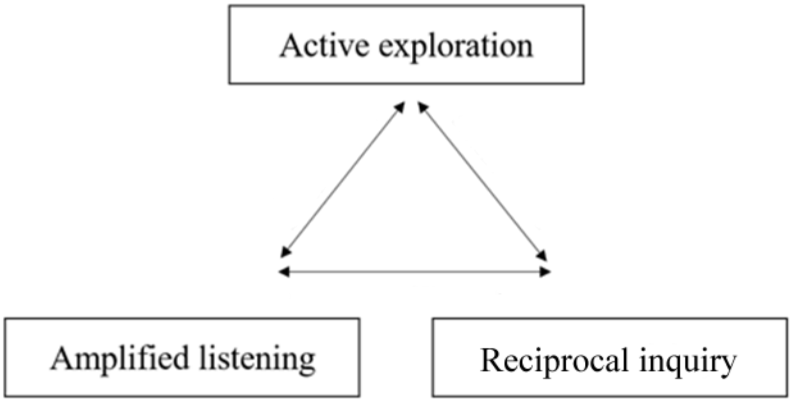

Figure 5.3. Moments and activities of the clinical negotiation with knowledge

Active exploration emphasises the practitioner's and patient's consideration of multiple aspects of the patient's health issues. During active exploration, the knowledge work of the practitioner consisted in asking general questions and being interested in different types of information, as well as in the patient as a person. In turn, the knowledge work of the participants consisted in elaborating and reporting on the various circumstances related to their health problems.

Amplified listening was the moment in which the participants reflected as the practitioner created the conditions for them to feel comfortable talking about their health problem. Such reflexive knowledge work led some participants to reach a new awareness or see a way forward themselves. Engaging in this reflexive knowledge work together with the clinician was appreciated by the participants, as it allowed for a reflection focused on health and recovery.

As the doctor listens to the patient's insights, s/he engages in reciprocal inquiry. For the doctor, this process is characterised by the application of clinical knowledge as well as knowledge of the patient' own circumstances, while being open to change and flexible regarding treatment options. For the patient, this process consisted in evaluating and weighing the doctor's proposed treatment options against their own goals. An important aspect of this process was its reciprocity, namely the mutual involvement and contribution of both parties during the negotiation, which made the participants feel respected in their capacity as persons with a valuable illness experience.

Summarising the analysis: An overview of the participants' knowledge work in the context of their healthcare experiences

In Chapters 4 and 5, I presented the results of the empirical work of my doctoral research, focusing on the analysis and integration of individual interviews and focus groups data (and I return to the strengths and limitations of this approach in Chapter 6).

Throughout both chapters, I explored the knowledge work of people with long-term conditions in the context of their healthcare experiences. I started from presenting their activities of learning by exploring, and then described their acquired experiential knowledge. Then, I focused on the participants' attempts to bring such knowledge to primary care settings, and described challenges to knowledge integration, but also successful ways for the participants and their doctors to integrate different types of knowledge during the clinical encounter. I summarised the themes and sub-themes described throughout both chapters in figure 5.4.

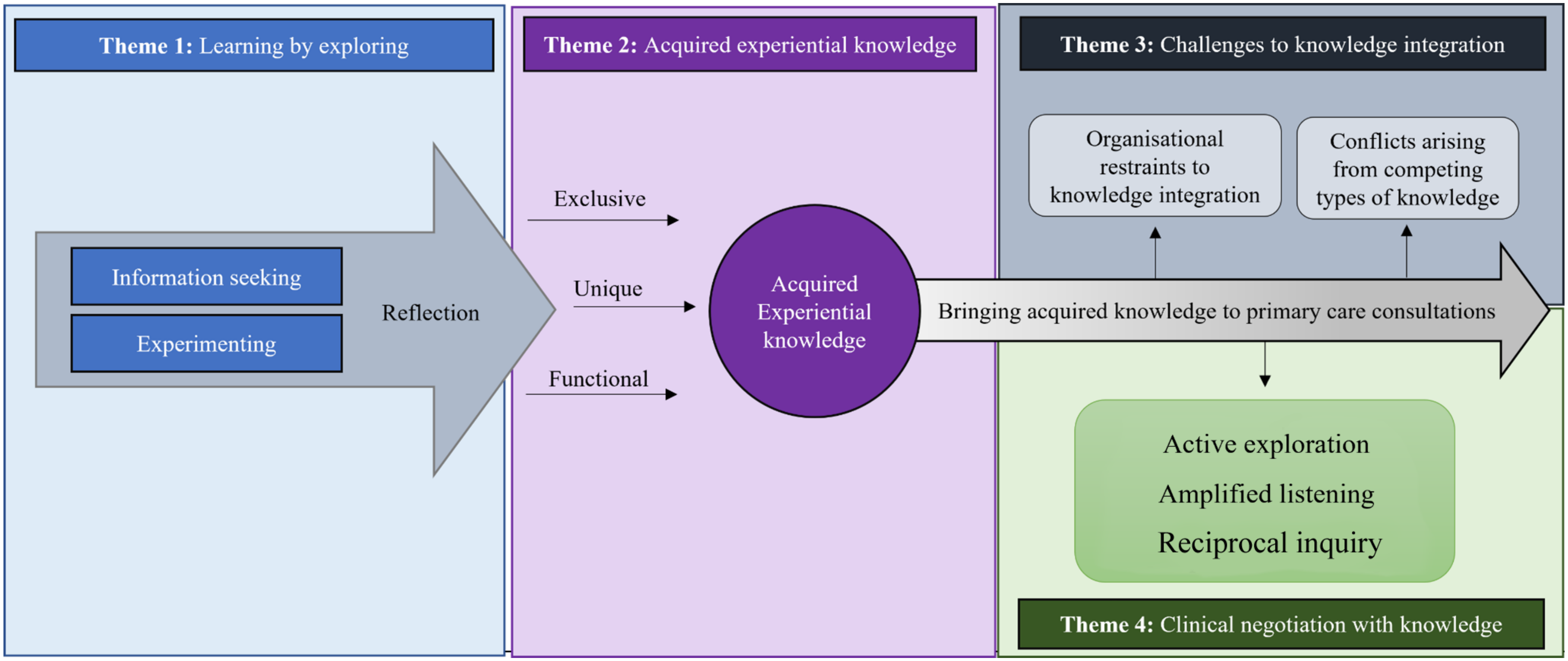

Figure 5.4. Themes and sub-themes presented throughout chapters 4 and 5.

The participants in this study showed that they engaged in learning about their conditions throughout their illness experience. This happened as their reflections accompanied activities of information seeking and experimenting, eventually leading to the acquisition of new experiential knowledge that was exclusive, unique, and functional.

The participants tried to share this knowledge with health professionals, yet experienced difficulties bringing it to primary care settings. On the one hand, organisational restraints made it hard for both patients and staff to address complex problems. On the other hand, conflicts over clashing types of knowledge occurred, and some doctors were perceived as not valuing patient's knowledge, or not taking it into account seriously.

However, positive experiences of knowledge exchange in primary care settings were also present in the dataset. They describe a non-linear clinical negotiation with knowledge in which both doctor and patient explore the patient's complex illness experience through active exploration, amplified listening, and reciprocal inquiry.

In the next chapter, I reflect on the role of the knowledge work of people with long-term conditions for person-centred clinical consultations, and present a critical examination of how the clinical negotiation with knowledge described by my analysis can strengthen and advance person-centred healthcare. I thus introduce the principle of epistemic reciprocity, and locate it in the wider discourse around patient knowledge and applied epistemology. Finally, I reflect on the implications of my findings for research, practice, and education.

Chapter 6 – Patient knowledge work and epistemic reciprocity: a critical examination of changes needed to strengthen person-centred healthcare

This thesis started by recognising a gap between the policy and public desire for person-centred care, and the reality of its declining experience reported by people with long-term conditions. Drawing on a growing body of literature on epistemic injustice, I proposed a need to consider if and how an analysis of the knowledge work done by adults with chronic conditions in the context of their healthcare experiences could illuminate changes needed to support person-centred primary care. Starting from this main question, and informed by the emerging analysis, I outlined three aims: (1) to develop a critical understanding of the essential aspects of person-centred care from the perspective of people with long-term conditions; (2) to systemically describe the knowledge work of people with long-term conditions in the context of their healthcare experiences; (3) to critically consider whether changes in approaches to understanding and supporting patient knowledge work can foster the enhancement of person-centred care. Whereas the first aim, along with the meta-ethnography, have been discussed in Chapter 2, this chapter will focus on the second and third aims of this study, while also presenting a critique on the totality of the findings of my PhD research.

My meta-ethnography allowed me to consider how the current evidence base on patients' conception of person-centred care may contribute to explaining its perceived lack as described by people with long-term conditions. This was possible by highlighting how epistemic aspects of care, though under-recognised and addressed in healthcare settings (e.g., because of the occurrence of epistemic injustice), are an essential aspect of person-centred care (along with organisational and relational aspects).

Further analysis on my empirical work recognised conflicts between patients' and doctors' understanding of illness and need, which did not match patients' wishes for person-centred care. I start by considering that this example of epistemic injustice may be due to a scientific versus experiential knowledge duality created by epistemological assumptions, and a duality that neither practitioners nor patients are equipped to handle with confidence. In this context, the results flag the importance of two key concepts, namely (1) the role of patient knowledge work in person-centred care, and (2) the clinical negotiation with knowledge. I discuss both of them and argue for a new overarching concept of epistemic reciprocity as a principle that guides the clinical negotiation and fosters the co-creation of new knowledge of patient experience and need through the interactive knowledge work of both patient and doctor.

I critically examine this new concept of epistemic reciprocity through consideration of the existing literature on patient knowledge and applied epistemology, and then present a review of this study's strengths and limitations. Finally, I consider the findings' implications for clinical practice, education, and research.

6.1 The role of patient knowledge work in person-centred care

In chapter 2, I presented the meta-ethnography that I carried out to identify the key aspects of person-centred care from a patient perspective. This meta-ethnography described three main aspects necessary for person-centred care – organisational, relational, and epistemic. These were defined through the patients' experiences of healthcare settings as a battlefield and/or a maze, and through the importance of their sense of personhood and of processes of patient enablement in those settings. Instances of epistemic injustice (defined in Chapter 1, page 21) were numerous across the review dataset, thus I decided to focus on the knowledge work of people with long-term conditions in the second part of my doctoral research.

My subsequent empirical work described four elements – how people gain their knowledge, the characteristics of such knowledge, challenges upon bringing this knowledge to primary care settings (i.e., organisational restraints to knowledge integration and conflicts arising from competing knowledge), and how they use it in the context of the clinical negotiation. Firstly, my analysis described 'learning by exploring' as the knowledge work that participants engaged in to gain knowledge throughout their illness experience. This included activities of information seeking, experimentation, and reflection. These resulted in knowledge with a strong experiential character and refined through reflection independently or with other relevant people (e.g., other patients and clinicians). Such acquired knowledge about the illness was considered unique, exclusive, and functional, and therefore worth incorporating in clinical decision-making.

In this section, I go on to consider how my study participants use this knowledge in the everyday knowledge work of negotiating clinical care. I discuss patients' knowledge work during clinical consultations, and how this knowledge work serves to define person-centred care.

6.1.1 Describing patient knowledge work during person-centred clinical negotiations

The second aim of my PhD research was to systemically describe the knowledge work of people with long-term conditions in the context of their healthcare experiences. Whilst data in my study indicate that patients value experiential knowledge in making sense of their illness, other research both highlights the value of this also for professionals, and demonstrates how such knowledge that falls outside of guidelines can create a decisional conflict for them (Fleming *et al.*, 2017). This conflict was also experienced and described by the participants in my study (see section 5.1.2 in Chapter 5). Within my analysis, I described this epistemic challenge as a potential conflict between scientific/professional guidelines and experiential knowledge. However, the participants' accounts also demonstrated successful experiences of engaging in the knowledge work of clinical negotiations that involved active exploration, amplified listening, and reciprocal inquiry.

During active exploration, the emphasis is on both the practitioner's and the patient's examination of multiple aspects of a health problem. This aspect of care has been highlighted by the SAGE consultation model (Reeve, 2015), which describes the knowledge work of doctors utilising multisource data in the robust creation of new knowledge. My analysis also highlights the participants' own knowledge work in this moment of the consultation to create their own understanding of their health needs and circumstances. This consisted in examining their own situation and building a story while putting together relevant pieces of information regarding their health problem. It also included deciding which were the most relevant questions or pieces of information when the practice' rules did not allow for the discussion of multiple, complex problems. These attempts to synthesise bodily symptoms and life circumstances into a coherent account have been defined by Blume (2017, p. 91) as the articulation of the subjective knowledge of a person's body's "(mal)functioning". This embodiment of the illness, namely the attention towards and awareness of how the ill body behaves or "disturbs" the person (Svenaeus, 2013, p. 101), is particularly evident in my analysis of the characteristics of the participants' acquired knowledge. For example, in Ann's and Emma's alertness to their own symptoms (page 109), or Jane's effort not to listen to her body when it was deceiving her (page 110). In these examples, the embodiment of the participants' illness contributed to their knowledge work, by allowing them to develop knowledge that was functional, and that they could therefore use in and outside of the clinical consultation.

During the clinical consultation, expanding on and talking about related health problems allowed the participants to also engage in more reflexive knowledge work, as they were "listening to themselves". I described this moment as 'amplified listening', which allowed patients to reflect on their own situation so they could see a way forward for themselves. It is worth noting that amplified listening is different from the previously described concept of active listening (Rogers and Farson, 1957), which is encouraged and recognised within current professional training. Whereas active listening helps the doctor develop empathy by listening sensitively to the patient, the action of amplified listening is introspective. In amplified listening, the act of listening is done by the speaker themselves, with the potential to bring the person/patient to a new awareness that can further contribute to the clinical consultation. In view of this, we need to explore with clinicians and trainers the changes in clinical training needed to support a shift from active to amplified listening.

Several studies have pointed out the importance of reflexive processes in the knowledge work of general practice, though they tended to focus on the knowledge work of healthcare professionals. Baarts *et al.* (2000) proposed reflexivity as a strategy for GPs to understand patients' perspectives. A study by Koshi and colleagues (2017) suggested that reflexive practice can improve health practitioners' skills and provided a structure for healthcare professionals to make use of reflective practice. Finally, the PEARL study (Brookes *et al*., 2019) (Patient Experience And Reflective Learning), though involving patients in its design, aimed to develop a workplace-based toolkit to provide guidance on reflective learning for the clinical staff.

However, my analysis highlights the importance also for the *patient* to engage in reflexive processes, both during the clinical consultation – with the participation of the practitioner – and after, when they go back home and think about what was discussed during the consultation. While Jane (page 129) appreciated being able to reflect and see “flashes of a way forward” during the consultation, Ann (page 130) complained that she had to “go home and think about it”, with no practitioner participating in her reflexive moment. This concept of patient reflexive knowledge work during the clinical encounter is also found in the concept of inductive foraging, defined as the space of the clinical consultation in which symptoms are searched with an open mind (Donner-Banzhoff and Hertwig, 2014). Although inductive foraging once again focuses on the knowledge work of healthcare professionals, it also recognises that there are moments of the clinical consultation in which the patient is leading by providing an illness account as the doctor listens. Whereas Donner-Banzhoff and Hertwig describe how the doctor identifies unusual symptoms/circumstances in the patient’s account, my work adds to this by highlighting how the patient in turn furthers their awareness of their own illness, namely through reflexive processes and amplified listening.

As the patient is reflecting on their own experience, the doctor is integrating insights from the patient with their own knowledge drawn from internalised tacit guidelines, professional experience, and knowledge of context (Gabbay and Le May, 2010). This process requires compromising, as it draws on the doctor’s ability to put together heterogeneous information through reasoning and professional judgement (van Baalen and Boon, 2015). At this juncture, the participants’ knowledge work consisted in critically examining the doctor’s expressed thought process and negotiating treatment options with the practitioner. According to Botelho (1992), doctor and patient may start with different expectations of treatment options, but their negotiation work is not hindered by the potential differences between them, as long as both set out to discover which differences are important to the process and outcome of medical care. In my dataset, this happened for example when the doctor makes sense of the patient's goals, or the patient makes sense of how various treatment options suit their goals (see Victoria's case on pages 134-135, or William's case on pages 136-137). On the one hand, this negotiation requires a degree of interpretative work, as the doctor needs empathy and integrity to understand the patient's stance and needs (Toon, 2021), as well as competent use of an appropriate range of knowledges (Reeve, 2010). On the other hand, at this stage patients are also busy interpreting measurements, tests results, treatment options, and translating their meaning into practical consequences for themselves (Pols, 2014). For instance, when the doctor told Emily she could die, she weighed that information and decided not to go to the hospital, but to stay at home ("If I'm gonna die, I'm gonna die at home", page 138). When the doctor told Oliver he would get a certain type of antibiotic (pages 120-121), Oliver replied that those would not work on him. Matt (pages 111-112) interpreted his symptoms as a form of arthritis, which he had in the past, and insisted with his doctor (hence negotiating his illness experience) that this was his problem. The participants were engaging in interpretive work as they weighed the doctors' arguments or presented their own counterarguments, as in these cases such differences between the patients' and the doctors' viewpoints were crucial and were not open to compromise.

Thus, we see examples of activities of reciprocal inquiry that allowed both practitioner and patient to come to a shared understanding. Reciprocal inquiry unfolded throughout activities of interactive knowledge work which occurred in different moments of the consultation. My analysis highlights the importance of mutual interaction (i.e., reciprocity through the active involvement of patient and doctor), as knowledge creation calls for a degree of mutuality and dialogical exchange (du Toit, 2003; Quinlan, 2009). Such reciprocal and interactive aspect of the doctor's and patient's inquiry was very important to the participants, who emphasised how lack of involvement and reciprocity in knowledge building activities made them feel not respected as persons.

This highlights an extended role for patients and professionals in the process of developing mutual understanding. Dowrick (2017, p. 135) wrote that healthcare professionals should engage with the selves of patients "with skill, curiosity and wonder". This recognises long standing expectations that good doctors should be listeners (Kermode-Scott, 1995; Lupton, 1997). However, my analysis demonstrates that patients also want to be good listeners – to listen critically to their doctors and so understand them (see Nora's example on page 139). Perhaps we need to recognise that patients should also be encouraged and supported to engage, like Dowrick wrote, with the selves of doctors with their own skills, curiosity and wonder.

To summarise, during clinical negotiations, patients are able to engage in different types of knowledge work: synthesising multiple aspects of their own health problems into coherent accounts, listening to themselves and reflecting, critically examining the doctor's statements, negotiating, weighing treatment options, and making sense of new information. Successful interactions that allowed for this knowledge work led to the achievement of person-centred clinical consultations, which I define in the next section.

6.1.2 Defining the person-centred clinical consultation grounded in patient knowledge work

The clinical consultation discussed in the previous section did not unfold in a set, linear way, hence diverging from what has been observed in other consultation models. Older consultation models (Byrne and Long, 1976; Stott and Davis, 1979) describe a linear and more doctor-centred process in which the practitioner starts from problem identification and uses problem solving skills to find the best course of action. Still, a checklist approach, which may resonate with many physicians as a framework for decision-making, may not resonate with patients' own models of decision-making or construction of their illness experience (Sackett *et al*., 1985; Charles *et al.*, 1997).

More recent person-centred models of clinical consultations have been proposed, that focus on aspects of care such as partnership, doctor-patient communication, engagement, and patients' ideas (Little *et al*., 2001; Illingworth, 2010; Santana *et al*., 2018). However, whereas the framework proposed by Santana *et al*. (2018) describes a person-centred process as one that focuses on integration of care as well as respectful and compassionate care, it does not address the negotiation aspects of the doctor-patient interactions. Little and colleagues (2001) address the patient perspective and identify the importance that mutual discussion has to patients. However, their model does not elaborate on epistemic aspects (such as the patient's and doctor's reflexive and interpretive work) in said discussion.

My analysis therefore highlights a key gap in these previous models, namely the need to recognise that a person-centred clinical consultation starts with a 'negotiation with knowledge'. Such consultation requires interaction, because it unfolds as a negotiation, and has epistemic value because it is grounded in both the doctor's and the patient's knowledge work. Thus, my findings resonate with earlier consultation models' emphasis on collaboration, but extend previous thinking to also focus on the epistemic aspects (i.e., knowledge work) of the clinical consultation as described in the previous section. In consideration of this, my proposed new definition of the person-centred clinical consultation is that of a negotiated exploration of the patient's complex experience, grounded in both the patient's and the doctor's knowledge work, and that values and enhances the patient's learning journey.

In summary, in this section I have systemically described the knowledge work involved in person-centred clinical consultations as experienced by patients. I have noted how, whereas the literature on knowledge work in healthcare settings has focused more on healthcare professionals, the patients' knowledge work described by my study resonates with the knowledge work of professionals described by Donner-Banzhoff and Hertwig (inductive foraging) or Gabbay and Le May (use of internalised and tacit guidelines for clinical decision-making). Furthermore, I have offered a definition of the person-centred clinical consultation as a negotiated exploration of the patient's complex experience grounded in both patient's and doctor's knowledge work.

In the next section, I address the third aim of my study, by presenting a critical reflection on how approaches to this knowledge work can strengthen person-centred care by allowing for the integration of different types of knowledge.

6.2 Examining changes needed to support person-centred care: Towards epistemic reciprocity

In this section, I introduce the principle of epistemic reciprocity as I address the third aim of my doctoral research, namely, to critically consider whether changes in approaches to understanding and supporting patient knowledge work can foster the enhancement of person-centred care.

Firstly, as highlighted by my qualitative evidence synthesis (Chapter 2) and my data analysis (Chapters 4 and 5), there were several instances in which people with long-term conditions were affected on a personal level when their knowledge work was excluded from clinical practice. Examples from both the meta-ethnography and my empirical work include feeling like an "animal at the zoo" (page 46) and invisible to the doctors (pages 140-141). In both examples, the professionals were discussing the patient's situation or were making decisions about the patient without asking for their contribution. However, if we want to foster person-centred care, we need to critically examine instances of such dehumanisation, as it takes the "person" away from person-centred care. According to Schmidt (2019), in these cases the doctors were denying these patients of status within their epistemic community. As the patient becomes an object rather than a subject of science (Benham-Hutchins *et al.*, 2017), their dehumanisation begs for a reflection on the weight of epistemic injustices, as Miranda Fricker (2007) wrote that when a person is denied the epistemic credibility they deserve, such injustice affects the person's sense of identity and self-esteem.

I have already demonstrated that the capacity for the interactive knowledge work of the clinical negotiation is a key part of person-centred care. Within the data, I highlight examples of patient and doctor working together to create a mutual understanding of a problem, and so define treatment options. I propose that this work can be described through the lens of epistemic reciprocity, a novel principle that guides the clinical negotiation and fosters the co-creation of new knowledge of patient experience and need through the interactive knowledge work of both patient and doctor.

In Chapter 2, my meta-ethnography highlighted that person-centred care has three interrelated aspects – relational, organisational, and epistemic. My empirical analysis further demonstrated the interrelation between these aspects. For example, when relational and epistemic aspects of care combined well, then patients described person-centred outcomes. Victoria (pages 134-135) managed to change her medication plan after her doctor trusted her judgment by prompting her to reflect on her body's readiness to stop taking a certain drug. Jack described that being looked after means having a GP who genuinely reciprocates the patient's interest, thus building a rapport as well as knowledge of each other's circumstances (pages 124-125).

My interpretation is further supported by observations of what happened when a clinical negotiation guided by epistemic reciprocity was not happening. This was manifested in different ways. For example, Thomas (page 133) complained about a perceived lack of knowledge of his GP, and Oliver (pages 120-121) and Eva (pages 135-136) complained about their GP's refusal to take their insights into account for decision-making. Angela (page 132) complained about the doctor not responding to what she was saying. In all these cases, the participants were prevented from engaging in meaningful knowledge work with their doctors. In Thomas' case, the doctor did not share with him any clinical insights and opinions, hence Thomas did not know how to reflect and make sense of his condition. Oliver and Eva wanted to engage in knowledge work by negotiating with the practitioner, but felt like their insights were not taken into account. Angela's attempts at engaging in knowledge work with her doctor were met with a lack of reciprocity, as she did not see her doctor trying to interpret and make sense of how she was feeling. In all these cases, the participants were all unable to engage in meaningful knowledge work, hence person-centred care was not achieved during the consultation.

Therefore, my analysis highlights that epistemic reciprocity is crucial to enhancing person-centred care by virtue of enabling the robust use of experiential knowledge from both parties in guiding clinical decision-making and assessment.

I further refined the development of this concept through an examination of the existing literature on patient knowledge and applied epistemology, which I present in the next section.

6.2.1 Locating epistemic reciprocity in the wider discourse on patient knowledge and applied epistemology

My findings resonate with the findings of Loftus (2018), who recognised the challenges of the scientific/experiential knowledge duality and stated that many practitioners today are not equipped to handle this duality with confidence. However, while several GPs feel that they lack skills in interpretive practice and permission to rely on other forms of knowledge for clinical decision-making (Reeve *et al.*, 2013), Pols (2014) pointed out that patients also find it difficult to bring home what they have learned at the clinic. Nonetheless, my analysis of the participants' experiences of their clinical consultations indicated that experiential knowledge could be integrated in clinical decision-making in a successful way. Such positive clinical negotiations with knowledge were characterised by epistemic reciprocity, a concept that I developed by considering changes in approaches to patient knowledge work needed to strengthen person-centred care. This concept resonates with other concepts from the literature on patient knowledge and applied epistemology, as I explain in the following paragraphs.

Epistemic reciprocity first builds on the concept of epistemic injustice, which considers how certain epistemic practices can be unjust towards particular knowers (Pohlhaus, 2017). As examples of epistemic injustice were numerous in my dataset, the idea of epistemic reciprocity stems from a reflection on ways to prevent such injustice, based on constructive epistemic interactions between doctor and patient. A related concept is that of epistemic humility, introduced by Grim and colleagues (2019) to indicate the doctor's reflexive awareness of their own assumptions, which in turn fosters openness to the patients' interpretations. Whereas epistemic reciprocity shares with epistemic humility a focus on openness and reflexivity, it also differs from it in that it requires that patients are also enabled and encouraged to be open and reflexive during the clinical consultation.

Epistemic reciprocity also ties in with the concept of patient knowledge and experiential expertise, defined by Castro *et al*. (2019) as complementary to professionals' expertise, and transferable to other persons or situations.

Though epistemic reciprocity has a more interactional focus, as it guides the clinical negotiation with knowledge, it does so by recognising experiential expertise and the importance of integrating different types of knowledge. This has implications for knowledge co-production in healthcare, defined by Filipe *et al.* (2017) as an exploratory space and a generative process that leads to different forms of knowledge. I suggest that epistemic reciprocity thrives in that space, and guides the process that leads to new knowledge during the clinical consultation through the knowledge work discussed in § 6.1.1.

However, a reflection on patient knowledge cannot prescind broader issues of epistemology. From an epistemological point of view, the use of patient experience as evidence is discussed by Renedo and colleagues (2018), who argue that patient experience is not just an epistemic commodity, but is part of a relational process in which patient and doctor engage with each other’s perspective without imposing their own. This relational process resonates with Gadow’s (1995) dialectical development, which recognised health professional’s progression from a position of disengagement to one of intersubjectivity in which the patient is involved in expressing a combined understanding of the clinical narrative. In this model, the engagement of both nurse and patient makes them co-authors of the clinical narrative (Gadow, 1994). Whereas epistemic reciprocity evokes this intersubjective, combined understanding through its interactive and relational aspects, it adds to Gadow’s dialectical development by highlighting how patients can engage in such intersubjective work, for example through active exploration and reflection.

To conclude, with its focus on mutual and reflexive integration of different types of knowledge, epistemic reciprocity draws on an epistemology that is capable of including, rather than excluding, the contradictions that are inherent in each unique experience (Pound, 2013). This is in line with the ideas expressed by sociologist de Sousa Santos (2014), who pointed out that we need a new epistemology, which does not judge each type of knowledge by the same standards, but affirms the diversity of knowledges by defining the conditions that validate each of them without any epistemic sovereignty.

6.3 A critical review of the application of quality criteria to my work

In this section I consider the strengths and limitations of my doctoral research, which recognises the characteristics of patients' knowledge work and the centrality of epistemic reciprocity in person-centred care. Whereas strengths and limitations of the meta-ethnography are discussed in Chapter 2, here I provide a critical review of the methodology of the empirical work of my PhD.

I discuss strengths and limitations in relation to the four primary quality criteria outlined by Whittemore *et al*. (2001) and described in Chapter 3 (§ 3.3). In each section, along with the primary quality criteria, I also reflect on and address the secondary criteria.

6.3.1 Credibility, thoroughness, and congruence

As described in Chapter 3, credibility as a criterion demonstrates that the findings accurately represent the experiences of the participants. In order to ensure credibility, I recorded all the interviews and focus groups, and transcribed them as soon as feasible, and no later than two days after the interview date. I also took fieldnotes (Appendix H, page 277) to document any relevant information that could not be documented through audio recording (e.g., non-verbal behaviour and contextual observations). During data analysis, to enhance the credibility of my findings, I checked my interpretations against those of my supervisors (Prof. Joanne Reeve and Dr. Paul Whybrow), who both coded one transcript each, and followed closely the data analysis process through monthly meetings. To further strengthen the interpretive process, I kept a reflexive approach to my research, while also engaging in multiple iterations of data analysis, and in the analysis of differences and contradictions within and between datasets. Whereas this was a long and complex process, I consider it a strength as it allowed me to achieve a full and in-depth understanding of the phenomenon (i.e., the participants' knowledge work in the context of their healthcare experiences).

However, potential limitations in the interpretive process are also present in my study. For instance, the participants' perception of my role as a researcher from the Hull York Medical School might have influenced some of their answers to my questions about person-centred care. This was the case of

Victoria, whose reply to my question on person-centred care indicated that she thought that I was looking for a correct answer, rather than an opinion.

> I: About the doctor that reduced your medication when you asked him to – if he had said no, do you think that could have still been person-centred care?
> Victoria: It would have been… he'd be going on the medical model, wouldn't he?

On the one hand, Victoria's background was in nursing, which influenced her reply. On the other hand, her checking with me for a confirmation indicated that she perceived that my question was investigating her knowledge, rather than just her opinion. Therefore, it is possible that a different interviewer, with a different background, would have received a different answer, leading to a potentially different interpretation of Victoria's perception of person-centred care in that instance.

On a similar note, a limitation of interpretative phenomenological analysis (IPA) lies in the difficulty differentiating opinions from experiences (Tuffour, 2017). To overcome this limitation, I designed the interview schedule so that it would focus on experiences (e.g., "What happened" questions) while also including follow-up questions to explore feelings and thoughts upon such experiences, and some questions to explore opinions. For instance, in the previous example, I was asking Victoria for an opinion. However, in her account on pages 134-135, she was describing her experience of negotiating with her doctor.

Whereas member checking has been proposed as a strategy to enhance the quality of the interpretation in qualitative research (Lincoln & Guba, 1985), I decided to not adopt it in my study. On the one hand, member checking is incongruent with an interpretive approach, as validation is not the aim of interpretive research, which allows for variety and dynamicity in the participants' perspectives. On the other hand, member-checking might even end up being a threat to the rigour of the interpretation, as the participant might overemphasise (or underemphasise) certain concepts upon revisiting them (McConnell-Henry *et al.*, 2011).

Similarly, although triangulation is considered a way to check the credibility of the findings when multiple methods are used (Patton, 1999), I did not triangulate my data, as I did not believe that checking lived experiences against opinions and beliefs was appropriate in the context of an interpretive epistemology. Furthermore, in the context of a realist perspective, which dismisses the possibility of the achievement of an absolute truth, checking data or methods against each other to decide which findings to confirm (or reject) would be inappropriate. Therefore, I opted for an integration of the findings instead, which consisted in exploring multiple aspects of the same phenomenon, as I deemed it more appropriate and compatible with my subtle realist/interpretivist approach.

As regards thoroughness (i.e., the comprehensiveness of the sampling and analysis strategies), a strength in my study is that the recruitment and data collection/analysis strategies allowed for the collection of in-depth research data that led to a nuanced and thick description of patients' knowledge work and clinical negotiations. Still, this study addressed a specific group of participants, and all of them were relatively active patients, as they were part of either a patient support group or a patient participation group. This is important for interpreting the findings, which heavily focus on knowledge and how it is built through the participants' illness experience. It is possible, for instance, that patients that engage less with health services or patient support groups have different priorities throughout their illness experiences. Along the same lines, people with moderate to advanced dementia or cognitive impairment (who have been excluded from this study) may have a different way to learn and develop knowledge about their conditions, or to engage with clinicians.

Moreover, whereas the focus groups were quite balanced in terms of gender representation, the same cannot be said for the individual interviews (fourteen women and six men were interviewed). This is partially due to the study's ethical arrangements, as it was mostly women who contacted me to express interest in participation, with a possible explanation being that women have been found to discuss and report on health issues more often than men (Merrill *et al.*, 1997). On the other hand, a more balanced gender ratio was observed in focus groups because several women registered to participate alongside their partners. Still, this is not a major limitation in the context of a phenomenology-based study, in which the most important characteristic of the participants is that they have experience with the phenomenon (Moser and Korstjens, 2018), which in my study's case was the participants' knowledge work in the context of their healthcare experiences. In view of this, a strength in my study's sample lies in the variety of other relevant characteristics, such as type of conditions and backgrounds, and being registered to different general practices. Such variety, along with the integration of the findings of both interviews and focus groups, allowed me to analyse a comprehensive range of experiences related to the participants' knowledge work (e.g., the knowledge work of people with diabetes and that of people with a rare lung condition; the knowledge work of people in a friendly and accessible practice, and that of people in a practice they felt detached from; the knowledge work of participants that were also health professionals, and that of participants that said they did not know much about their condition when it started).

Upon examining my study's congruence, a strength of this study is that I combined two datasets (focus groups and individual interviews) by treating them as mutually informative (as described in Chapter 3). Congruence in the integration of interviews and focus groups was achievable because they were designed so that both could be compatible with a subtle realist ontology and an interpretive epistemology. Furthermore, I designed data collection tools so that both methods could complement each other, with the individual interviews guide focusing on lived experiences, and the focus group guide focusing on opinions and group discussions. Moreover, the analysis of the interviews had a strong idiographic focus, whereas the focus groups provided a wider context/frame to further define knowledge work processes. Finally, I interpreted my findings in the context of the wider literature by providing evidence that supports my interpretations, and reflections on differences between my findings and similar concepts (as presented, for example, in section 6.2.1, where I reflect on epistemic reciprocity in the light of the wider literature on related concepts).

6.3.2 Authenticity, vividness, and explicitness

Authenticity is another primary criterion of validity defined by Whittemore and colleagues (2001), and refers to the extent to which the participants' perspectives, and their differences, have been portrayed accurately. As regards authenticity in IPA, a potential limitation of my study is the relatively large number of transcripts (i.e., 18) analysed. Still, over time phenomenological studies have included different numbers of participants or transcripts, from 50 (Fischer and Wertz, 1979), to 30 (Stevick, 1971), 28 (Idczak, 2007), 25 (Mruk, 1983), 16 (Papp *et al*., 2003), and 3 (De Koning, 1979). Nonetheless, I aimed to achieve authenticity by working to keep the idiographic focus of IPA with 18 transcripts. In order to do this, I followed the guidelines by Smith (1999) on performing IPA with larger numbers of transcripts (as described in Chapter 3, section 3.2.4, and in Appendix H on page 277), which allowed me to achieve depth in the analysis.

For both interviews and focus groups, a strength in this study's authenticity is that I adopted an inductive approach to data analysis, hence all codes and themes were generated from the data. Then, in order to keep an idiographic focus, which was particularly important in the case of the individual interviews, I analysed each interview on its own, and separately from the others. I also developed a thematic summary for each participant, so that the most thematically rich concepts could be understood in the context of each participant's individual account. Furthermore, as suggested by Creswell and Miller (2000), I engaged in peer debriefing as my supervisors reviewed my data and research process and helped me uncover unchallenged assumptions (see section H.5 of Appendix A, page 282, for an example).

As regards vividness (i.e., the thickness and clarity of the descriptions of the phenomenon) a strength in my study lies in the depth of the analysis of focus groups and interviews, which consisted in multiple iterations of data analysis through a back-and-forth movement between data and datasets. Vividness was further enhanced by academic discussion with my supervisors, which allowed me to clarify and improve my descriptions and interpretations. This resulted in a rich description of the participants' knowledge work, which included how they acquired their knowledge, the characteristics of such knowledge, and how they use it during clinical consultations.

Finally, to ensure explicitness, the study process has been thoroughly documented from the start, as I wrote a study protocol during the first year of my doctoral research and kept documenting the research process by writing interim reports on objectives and data analysis plans, as required by the Hull York Medical School. To allow for insights in my research judgement, I included a description of the data analysis process in Appendix H (page 277).

6.3.3 Criticality, integrity, and sensitivity

Criticality and integrity are the third and fourth primary validity criteria that I applied to my work. As described in Chapter 3, these demonstrate both the quality appraisal process (criticality) and a self-critical attitude that allows for recursive quality appraisal and humble presentation of the findings (integrity) (Johnson, 1999). Therefore, a strength of my study is that I explicitly applied a series of validity criteria to evaluate the rigor and robustness of my findings, as demonstrated in Chapter 3 (section 3.3) and in the critical review in this section. A limitation of the application of these criteria in my study lies in the limited focus on creativity as a criterion of validity. However, from a subtle realist and phenomenological perspective, it is important to stay as close as possible to an accurate description of the phenomenon. Furthermore, Whittemore *et al*. (2001) allow for flexibility in the adoption of secondary criteria, and so I decided to address creativity in this study mainly by incorporating questions to stimulate the participants' creativity and/or reflection in both focus groups and interviews.

As regards integrity, a strength of this study was the regular evaluation of the research project. Not only monthly supervision meetings allowed for the constant re-assessment of research aims and objectives, but formal assessment by an external panel of academics (Prof. Liz Walker and Prof. Ivana Markova) also took place twice a year for the first three years of my doctoral research.

Finally, as regards sensitivity, a strength of this study lies in the involvement of multiple PPI representatives at the planning stage, which contributed to the improvement of appropriateness and relevance of the data collection and recruitment material. However, contextual and ethical issues addressed by this study mainly apply to the setting in which it has been conducted. This was the UK healthcare system, where the NHS is free at the point of entry, which means that medical care is available for free, and without payment (except for some services, like dental care), for all UK residents. People who live in countries with different healthcare systems might have different ideas and expectations about healthcare services in general and, more specifically, about negotiating their illness experience with health professionals during clinical consultations.

Conclusions and implications for research, practice, and education

At the start of my thesis, I acknowledged the perceived lack of person-centred care as described by the experiences of people with long-term conditions, and introduced epistemic injustice as a framework to understand such experiences. Then, I set out to investigate what an analysis of the knowledge work done by adults with chronic conditions in the context of their healthcare experiences could tell us about changes needed to strengthen person-centred primary care.

I started by addressing my first aim, which was to develop a critical understanding of the essential aspects of person-centred care from the perspective of people with long-term conditions. I achieved this aim through a meta-ethnography of published research, and found that the most important aspects of person-centred care described by people with long term conditions are epistemic, relational, and organisational. These aspects are all connected and work together to foster the achievement of person-centred care for both patient and doctor. As instances of epistemic injustice were numerous across the meta-ethnography findings, the knowledge work of people with long-term conditions became the area of study I focused on in the second part of my doctoral research.

During the second part of my research, I conducted interviews and focus groups, and analysed and integrated their data to address my second and third aims, namely (2) to systemically describe the knowledge work of people with long-term conditions in the context of their healthcare experiences; and (3) to critically consider whether changes in approaches to understanding and supporting patient knowledge work can foster the enhancement of person-centred care.

Firstly, I described the knowledge work of people with long-term conditions in the context of their healthcare experiences. The participants in this study learned by exploring, which led to an acquired experiential knowledge that was exclusive, unique, and functional. During primary care consultations, person-centred care was achieved through a clinical negotiation with knowledge in which the patient's and doctor's interactive knowledge work unfolded through moments of active exploration, amplified listening, and reciprocal inquiry. The knowledge work of the participants in this context consisted in different activities, including synthesising multiple aspects of their own health problems into coherent accounts, listening to themselves and reflecting, critically examining the doctor's statements, negotiating, weighing treatment options, and making sense of new information.

After systemically describing the participants' knowledge work, and its role during clinical consultations, I reflected on how changes in approaches to patient knowledge work could strengthen person-centred care. To this aim, I proposed the novel concept of epistemic reciprocity, namely a principle that guides the clinical negotiation and fosters the co-creation of new knowledge of patient experience and need through the interactive knowledge work of both patient and doctor. While grounded in my data, the concept of epistemic reciprocity also resonates with literature on patient knowledge and clinical and applied epistemology, and draws on an inclusive epistemology that embraces, rather than excluding, the diversity of knowledges.

These findings have several implications, in particular for medical education, practice, and research.

As regards medical education, the presence of organisational elements among the aspects of person-centred care in my meta-ethnography, along with comments from my study participants, indicated that clinicians need to be enabled to engage in person-centred clinical encounters by the healthcare system organisational setup and, before then, by the very educational system that trains them to become healthcare professionals. Furthermore, my analysis demonstrated that being able to successfully engage in knowledge work during the clinical consultation led to positive outcomes. For example, the doctor's and patient's effort to engage with each other's point of view led them to achieve a shared understanding. This was experienced by Jane, who said that she became successful in the management of her conditions after she started working together with her doctors, rather than being at odds (page 130). This was particularly evident through reciprocal inquiry, in which the doctor had to be able to integrate, rather than filter out, different types of knowledge, while also keeping an open mind, as the achievement of shared understanding is grounded in the doctor's effort to go beyond their own frame of reference (Street, *et al*., 2009). According to Loftus (2018), this integration between doctor and patient perspectives starts with medical education. Therefore, it is worth considering integrating medical education curricula, in particular for primary care and general practice, with training in the philosophy of knowledge (epistemology), and the principles of epistemic reciprocity, thus framing person-centred care not as the ethical thing to do, but as the wise and competent thing to do. This also means training in the practice of the robust and safe construction of knowledge in practice (Gabbay and Le May, 2010), as well as in interpretive medicine, which consists in the use of a range of knowledges during the clinical consultation through reflective judgement (Reeve, 2010). Some such training resources on the knowledge work of clinical practice are currently being recognised, developed, and shared through the WISE GP programme (see www.wisegp.co.uk), an initiative that aims to develop scholarship skills across primary care professionals and patients.

As regards clinical practice, this study served to clarify that conflicts between patients and doctors are often inherently epistemic in nature, rather than being just due to a personal conflict, as doctors can be conflicted themselves as to how to apply their knowledge. With this respect, epistemic reciprocity and the person-centred moments described in this chapter provide a framework to understand the nature of clinical consultations and to reflect on the extent to which epistemic or relational aspects of care are embedded in the consultation process. Furthermore, it provides a framework to understand the clinical consultation from a patient perspective, and to guide it in a way that reflects patients' ideas of person-centred care.

Another implication for clinical practice stems from the importance of reflexive processes described by this study. Since epistemic reciprocity unfolds through a mutual reflexive effort, it is important for clinicians to not only reflect effectively (Koshy *et al*., 2017), but to also encourage and allow for the patients' own reflexive practice, as this study suggests that it is not just the doctor who acts as a hearer, or a listener, but the patient too. These implications echo Schmidt's observations (2019) that it is possible to promote epistemic justice by fostering people's ability to act as individual inquirers. In my study, this was possible when the participants were enabled to reflect and hence inquire with their doctors about their own treatment and possible treatment plans (see Mary, pages 102-103, who described how her reflection on the actual need for a gastroprotective drug led her to question it, so she raised the issue with her doctor, who agreed to take her off that medication). In considering the practitioners' workload, also highlighted by the study participants, allowing for such reflexive practice may need attention to the design of the consultation process at the practice level – including timing, headspace, pre-consultation and post-consultation work.

However, attention to these aspects of the consultation process requires addressing the contextual factors that affect doctors' capacity to engage in person-centred consultations. For example, the Quality and Outcomes Framework (QOF), a system that rewards professional activity in primary care based on certain quality indicators, was found to shape clinical consultations to the point that many patients with long-term conditions found them irrelevant, as the QOF's focus on evidence-based care constrained their priorities and concerns (Chew-Graham, *et al.*, 2013). In this context, GPs themselves have expressed that person-centred approaches are not properly accounted for by professional standards of clinical practice such as the QOF, which are "overly bureaucratic" and do not add much to the quality of care (Fisher, *et al.*, 2017, p. e153).

Similarly, regulatory requirements do not always allow GPs to comfortably engage in person-centred approaches. Whereas following clinical guidelines is encouraged, strict adherence to single-condition clinical guidelines, along with other systemic factors such as need for on-going medication reviews and time pressures, lead to overprescribing, which is problematic for both patients and health systems (Ridge, 2021). It has been suggested that person-centred medicines optimisation can be a response to problematic polypharmacy (Heaton, *et al.*, 2017); however, adopting person-centred approaches sometimes means deviating from the guidelines to tailor care to a specific patient, and when this happens clinicians have reported fear of litigation, hence preventing them from making truly person-centred decisions (Reeve, *et al.*, 2018).

Furthermore, the knowledge work of person-centred care can be hindered by the very own setup of the practices in which GPs work. Several participants in this study confirmed that their practices allow doctors and patients to address only one health issue per consultation, thus preventing them from managing complex and related problems. However, this study also showed that knowledge of the complex and varied circumstances around a patient's health condition is at the heart of the person-centred clinical consultation. Furthermore, the standard 10-minute consultation prevents both patients and doctors to engage in an in-depth exploration of the patient's situation, hence it needs to increase to give GPs more time to provide care (Royal College of General Practitioners, 2019). As the issues presented in these paragraphs pertain contextual and wider policy factors that affect the clinical consultations, they are often beyond the doctors' control. Therefore, it is paramount to address these issues if we are to achieve epistemic reciprocity and enable both patients and doctors to engage in meaningful person-centred knowledge work during clinical consultations.

Finally, this study also leaves some open venues that could be explored through further research. I did not include the experiences of younger people, or people with advanced dementia and cognitive impairment, who may have a different view on person-centred care and epistemic reciprocity, hence warranting a separate study. Furthermore, epistemic reciprocity can be used as a conceptual framework to investigate the learning, knowledge work, and clinical experiences of clinicians, as their views have not been included in this study, yet they are at the centre of the clinical consultation together with patients. Finally, further research could focus on developing, implementing, and evaluating guidelines and interventions to integrate epistemic reciprocity in clinical consultations, and to identify practical implications and pragmatic aspects of its implementation in clinical practice. Therefore, my findings flag the need to understand enablers and barriers to epistemic reciprocity in the clinical setting – using those insights to guide the redesign of healthcare to support person-centred care approaches.

As this study started from the problem that person-centred care is not being implemented meaningfully according to people with long-term conditions, I hope that these findings can serve to inform research, practice, and clinicians' understanding of person-centred care from a patient perspective, to ensure that people with long-term conditions are not only treated fairly, but also respected in their capacity as persons with a valuable experiential knowledge.

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Appendix A – Meta-ethnography's paper– Pre-proof version

The results of the meta-ethnography presented in Chapter 2 have been peer reviewed and published as a paper on the European Journal of Person-Centered Healthcare. In this appendix, a pre-proof version of the paper is available (references are presented in Vancouver style as required by the journal). Whereas the original paper includes the results of the quality appraisal as an appendix, in this thesis these have been reported separately in Appendix C.

What do the healthcare experiences of people with long-term conditions tell us about person-centred care? A systematic review.

Abstract

Introduction

Growing numbers of people now live with long-term conditions. For each person, the challenges are multiple and unique to that individual. In recognition of this, health policy places greater emphasis on the delivery of person-centred care (PCC). However, patients report declining levels of such care. One reason for this may be a mismatch between patient and professional/policy understanding of PCC.

Aim

To understand PCC from the perspectives of people with long-term conditions.

Methods

A systematic review of qualitative literature was conducted. Databases searched included ASSIA, BNI, CINAHL, the Cochrane Library, Embase, Medline, PsycINFO, PubMed, Scopus, Web of Science, and grey literature databases. Two reviewers independently screened and selected the studies, assessed their quality, and extracted data. Fifty-four records were analysed through meta-ethnography.

Results

Four themes emerged: the healthcare system as a battlefield, the healthcare system as a maze, patients' accounts of personhood, and the importance of patient enablement. A person-centred healthcare system is described by this review as one that values personhood and enables patients to build knowledge with their clinician in order to manage their illness in a safe, caring, and accessible environment.

Conclusion

PCC does not depend on the efforts of the clinician alone, but results from a collaboration with the patient and needs to be enabled by the wider organisational and educational systems. Efforts directed at the implementation of PCC might be bound to fail if the healthcare policy agenda does not address the role of the patient's personhood in clinical practice, and its integration in educational settings.

Introduction

Over the last few decades, the rising numbers of older people and prolonged time living with long-term conditions have put much strain on resource-limited healthcare settings. In such settings, the biomedical model has long been the dominant approach to clinical care, with its focus on treating single diseases and on "discovering the pathology rather than understanding the illness" [1 p1401]. However, such clinical orientation has contributed to the development of a plethora of guidelines that, if applied slavishly, could end up contributing to the patients' treatment burden instead of solving their health problems [2,3]. Therefore, more comprehensive and effective approaches to clinical care are needed in order to deal with the complexity of chronic conditions.

Nowadays, we see a resurgence in healthcare models that take into account not only the person's disease, but also his or her illness experience. A more person-centred approach, which recognizes the biopsychosocial dimensions of health, prioritizes the person's subjective experiences, and involves patients in decision-making processes [4], has been emphasised, as it is considered to be crucial in the management of chronic diseases [5].

Still, patient surveys have reported that healthcare professionals are not delivering or implementing person-centred care (PCC) in a meaningful way [6]. For example, in the United Kingdom, notwithstanding the commitment of successive governments to PCC [7], people with long-term conditions wish to be more involved in their own care, and are receiving care that does not meet their perceived needs, with inefficient use of contact time, scarce focus on information and education, and poor outcomes [8,9]. This is even more evident in primary care settings, where a recent survey has found that the indicators for PCC have deteriorated since 2017, and that some groups of people are less likely to report positively on the care they receive or report scarce involvement in their own care [10]. Whilst possible reasons for this are varied and complex, one explanation is that we do not have a clear, patient-derived view of PCC. Therefore, policy and organisational changes might have attempted to strengthen and improve the delivery of PCC in ways that did not always reflect the patients' own views and priorities.

So far, studies about what patients think of PCC have focused on specific constructs or settings [11,12] or were quantitative in nature [13]. Therefore, we set out to conduct a systematic review of the healthcare experiences of people with long-term conditions in order to get a more encompassing understanding of what PCC is from their perspective. Our review question was:

- What are the essential elements of a person-centred healthcare system as described by the experiences of patients?

Essential elements are those aspects of healthcare that have a positive impact on someone's healthcare experience (e.g., they resulted in positive outcomes, patients or study authors defined them as important or needed, positive feelings/satisfaction were expressed, and so forth).

Methods

We conducted a systematic review of qualitative studies following the steps described in the ENTREQ (Enhancing transparency in reporting the synthesis of qualitative research) guidelines of best practice [14]. We conducted a search of the following databases: ASSIA (Applied Social Sciences Index and Abstracts), BNI (British Nursing Index, now known as British Nursing Database), CINHAL Plus, the Cochrane Library, Embase, PsycINFO, Pubmed and Medline, Scopus, and Web of Science. WorldCat, Grey Literature Report, the INVOLVE Libraries, and OpenGrey were also searched in order to retrieve any relevant grey literature. Additional records were identified through reference list checking. The search was conducted between February 2018 and March 2018, and was updated in September 2019 (excluding grey literature databases).

The development of the search strategy was informed by the research questions and by other systematic reviews of qualitative studies about the experiences of people with long-term conditions. A combination of subject heading and keyword searching was employed depending on the database. A systematic review protocol was developed and registered online on PROSPERO (registration number CRD42018094380), where excerpts of the search strategies are available.

Eligibility Criteria

The studies' references, titles, and abstracts were transferred to a dedicated EndNote library. Two reviewers (MD and SP) independently screened all the records against the eligibility criteria, and compared their decisions. Whereas any disagreements or doubts emerged, they were solved through academic discussion, with a third reviewer (JR) being available in case they could not be solved. The eligibility criteria were defined as follows:

Inclusion criteria

- Qualitative studies that involve adults (>18 years old) with physical and/or mental chronic conditions;
- Studies that acknowledge person or patient-centred care;
- Studies published in English;
- Studies conducted in developed countries;
- Studies with mixed-methods designs whose qualitative component was substantial enough to allow for analysis;
- Studies conducted in primary or secondary care settings;
- Empirical papers (including reviews of qualitative studies).

Exclusion criteria

- Studies presenting exclusively quantitative data and methods;
- Meta-analyses, book reviews, study protocols, conference proceedings, commentaries, and systematic reviews of quantitative studies;
- Studies about:
    - Complementary medicine

    - Illness (not healthcare) experience
    - Other groups (e.g., caregivers, health professionals)
    - Specific groups (e.g. sex workers, veterans)
    - The creation, validation, or assessment of a model, intervention, toolkit, etc.
    - Telecare and home-based care
    - Care delivered by students/trainees
- Studies involving more than two stakeholder categories (e.g., patient, carers, and providers), or presenting the findings in an unclear way (e.g., “the participants said”);
- Exclusively methodological and/or theoretical studies.

Two flow diagrams (Fig. 1 and Fig. 2) documenting the screening process were developed in accordance with the PRISMA guidelines [15].

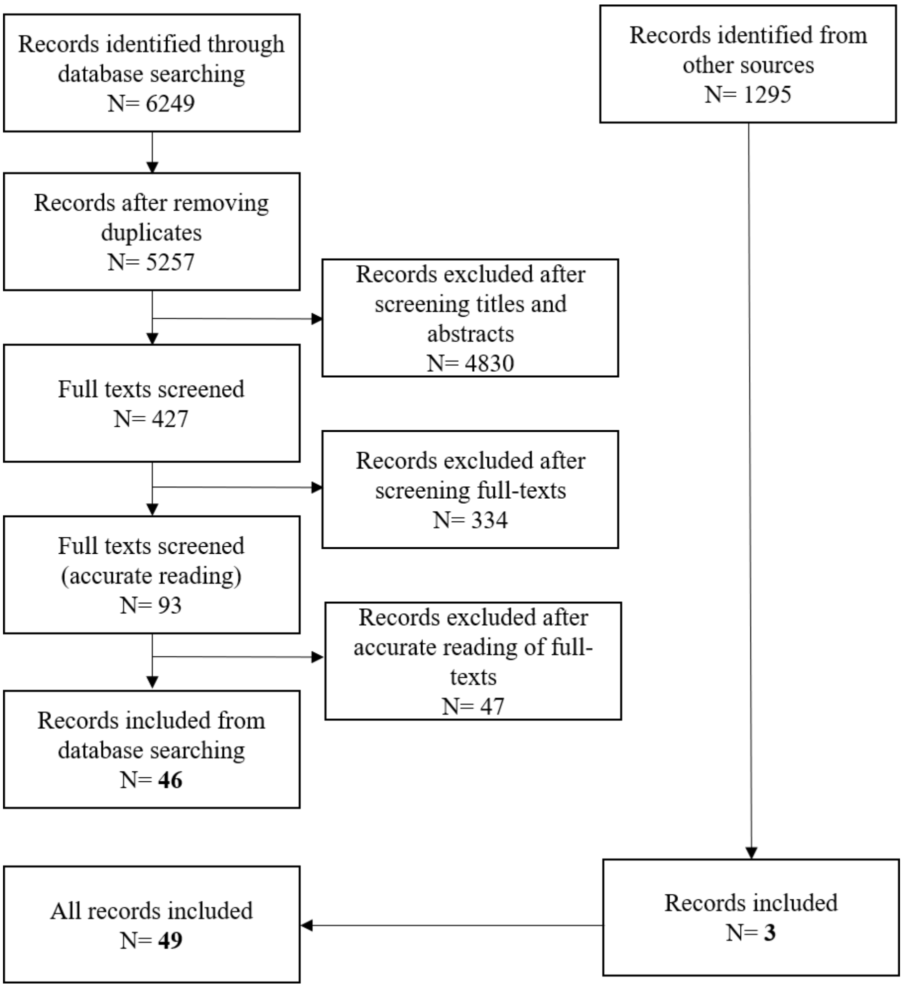

Figure 1. PRISMA flowchart – initial search (February 2018 - March 2018).

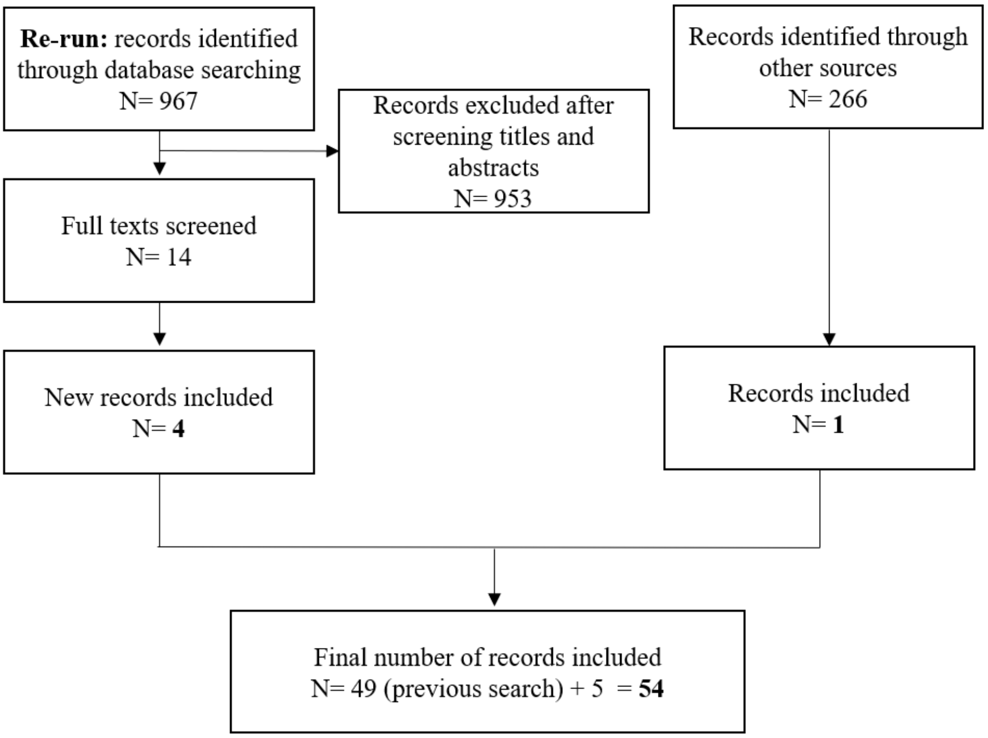

Figure 2. PRISMA flowchart – search update (September 2019).

Data Extraction and Analysis

Two reviewers (MD and SP) employed a data extraction form to independently extract study characteristics, the participants' demographics, quotes, and authors' interpretations. The electronic versions of each record were transferred to NVivo 12 (QSR International, Melbourne, Australia).

For the analysis, we opted for meta-ethnography [16] in consideration of its suitability for the exploration of people's experiences, and because it aims to develop a conceptual understanding of a phenomenon [17], as we wanted to understand the phenomenon of PCC. There are seven phases of meta-ethnography, namely (1) getting started, (2) deciding what is relevant, (3) reading the studies, (4) determining how the studies are related, (5) translating studies into one another, (6) synthesizing translations, and (7) expressing the synthesis. These phases have been described elsewhere [18,19]. More specifically, the analysis (steps 5 and 6) was carried out in two steps: reciprocal and refutational translation, and line of argument synthesis. During the reciprocal and refutational translation the studies' key concepts and themes were translated into each other (reciprocal translation), while any differences and inconsistencies between the studies were explored (refutational translation). Then, the line of argument synthesis was carried out to achieve an overarching interpretation by synthesising the findings that emerged throughout the dataset.

In particular, the translation was facilitated by dividing the studies in three groups according to their setting (primary care, secondary care, and mixed). The records within each group were analysed in chronological order, using thematic analysis. The themes that emerged from each group were synthesised together by drawing relationships between them. This process was informed by the authors' individual interpretation and academic discussion with the wider team, as well as by previous knowledge of the literature on person or patient-centred care.

Quality Appraisal

MD and SP carried out quality assessment independently, using the Joanna Briggs Institute (JBI) Critical Appraisal Checklist for qualitative research and for systematic reviews, as we considered its focus on congruence [20], and emphasis on the participants' voices compatible with the principles of meta-ethnography. Exclusion was contemplated only if a qualitative methodology was deemed incompatible with the aim of the study. Otherwise, studies were not excluded based on their quality, as our priority was that of capturing a wide range of people's experiences. Results of quality appraisal have been reported in Appendix A. Differences in scores were usually related to incomplete reporting (i.e., "unclear" answers on the JBI checklist).

Results

Fifty-four records were analysed. This number includes 46 qualitative studies, six mixed-methods studies, and two literature reviews (of which one was systematic). The studies presenting primary data brought together the views of 1882 adults with long-term conditions, plus an ethnographic study in which the number of participants was not reported. Most of the studies (22) were about a variety of chronic conditions, followed by chronic pain (9), mental illness (5), diabetes (4), cancer (4), stroke and/or brain injury (3), degenerative disorders (3), heart failure (2), chronic kidney disease (1), and frailty (1).

Four main themes emerged from the analysis: (1) the perception of the healthcare system as a battlefield, (2) the perception of the healthcare system as a maze, (3) the patients' accounts of personhood, and (4) the importance of processes of patient enablement.

In general, studies conducted in primary care settings tended to focus more on the clinician-patient relationship, whereas studies conducted in secondary care settings mentioned more often service efficiency and identification of patients' needs. On the other hand, the communication of relevant information was a common topic across all study groups.

Theme 1: The perception of the healthcare system as a battlefield

The perception of the healthcare system as a battlefield emerged through the participants' feelings of anger and fear to speak up when something was wrong, the occasional perception of health professionals' aggressiveness, and the appearance of war metaphors (e.g., "battle", "fight") across the dataset. For example, one participant used the word "army" to refer to a group of medical students accompanying their care team during clinical visits [21].

These data hinted at a perceived power struggle, for example when patients said they were afraid the doctor would "punish" them if they disagreed with them. In other instances, they believed that they had to fight to be believed [22], to defy paternalistic attitudes [23], and to access medical resources [24]. Such perception led some patients to believe that clinicians were unwilling to share information with them [25], or would actively get in their way to prevent them from getting information [26]. Several participants were afraid to be seen as a "bother", and thus refrained from asking for help [27,28].

"I sensed that I was troublesome to her and she didn't like me . . . this made me upset. I dare not communicate and talk anymore with her in the future" [29]

Contrasts were present also when role expectations differed between patients and clinicians. Whereas some patients (usually a minority) thought that clinicians were "the experts" [30,31], and should decide for them [32], in other instances people believed that nobody could understand their illness better than themselves, and wanted to be viewed as proactive patients with their own skills and expertise [22,33-35]. Reasons behind such different attitudes were investigated during the analysis. For example, patients tended to think that clinicians were the experts because they thought clinicians “trained for years” or “have the degrees” [31,32]. Patients accepted most of the clinicians’ decisions, especially when such decisions were communicated and explained clearly [30]. On the other hand, other patients thought of themselves as experts because they “know their body” [34], as well as the social, mental and physical consequences of their symptoms, which they said clinicians did not know [22].

When the goals of healthcare staff and patient differed, patients either accepted the situation [36,37], did not adhere to the treatment (or made their own medical decisions) [30,32,38], looked for a second opinion [38], or stopped using healthcare services altogether [39]. In other instances, patients would take the initiative differently, for example by trying to educate their physicians about their illness [40,41], or demanding to see “someone higher up” [32]. Still, for some authors, even seemingly “passive” behaviours like non-adherence or the adoption of unhealthy lifestyles in spite of the doctors’ advice could be seen as “powerful statements of self-determination” [39 p40].

Theme 2: The perception of the healthcare system as a maze

Patients had a hard time finding out which services were available, trying to access services and information, and coordinating the information collected across different settings. These people received care that did not meet their needs, in particular, information exchange and retrieval and identification of/access to health services. For example, even when the clinician was valued as an expert and a source of knowledge, organisational issues such as lack of time meant that patients were unable to find a way to get information from them [42].

In general, hospital settings were perceived to be less accessible than primary care settings, with longer waiting times, less flexibility, and scarce continuity [43]. Still, getting in touch with the health centre’s staff was difficult in primary care settings as well [31]. In this context, the participants emphasised the importance of relational continuity (i.e., seeing the same clinician every time) as it contributed to feelings of security and consistency [44,45]. Flexible continuity, namely timely access to care, and the practice staff's ability to make and change appointments efficiently [43] was also mentioned by the participants as a desirable aspect of care.

Patients also made recommendations to help them "navigate the maze"; examples are the presence of a care coordinator [27], availability of online and offline resources that people can access after discharge [21], and centralised information systems that could facilitate provider access to patient data [46].

Theme 3: The patients' accounts of personhood

The participants' perception of the healthcare system as a battlefield and/or a maze had a negative impact on their healthcare experience: feelings of frustration, humiliation, and isolation led some of them to lose faith in the system or in their doctor [31,47,48]. Such reactions indicated that the patients were affected on a personal level by what happened within the clinic's walls, as some of them complained about not being seen as "persons". The importance of personhood was also highlighted in a positive way, when some participants admitted that being seen as a person allowed them to "show the true reflection of self", giving them more confidence in the clinical environment [49 p15].

Nonetheless, negative feelings affecting patients on a personal level were common. For example, patients with long-term conditions have to deal with the fluctuating nature of their illness, and the feelings of uncertainty and anxiety that accompanied the most unpredictable or degenerative diseases. These could be exacerbated when these people did not manage to communicate effectively with the staff [28]. The lack of information and feedback left them with feelings of being met with nonchalance and being ignored, which caused them a degree of unnecessary concern and anxiety [34,45]. Feelings of anxiety were also associated with other aspects of the care process, such as receiving the diagnosis [50], accessing a saturated care system [51], or asking for help while fearing rejection [52].

Another feeling described by some participants was that of being neglected, or of their health problems being downplayed by health professionals. This was particularly true for older people, people with chronic pain, and residents of nursing homes [37]. The participants' sense of self-worth could be affected by this, as exemplified by the following quotes.

"Is it because I'm over 65, they're not doing anything about it?" [28]

"It is not until you sit in a doctor's chair yourself and live through the experience of telling them how much pain you are in […] that you can understand how worthless a patient with fibromyalgia feels in their eyes." [40]

Some patients also reported feeling labelled as hypochondriacs or drug seekers [53], or complained that their physical symptoms (e.g., pain and fatigue) were attributed to mental disorders [54], laziness, and stereotyping [22]. In such situations, some of them reported feeling dehumanised [54]. Examples of this were numerous, as the participants said that the healthcare staff made them feel like numbers [41, 55], objects (e.g., "a rock", a "piece of the furniture") [25,35,39], or animals [21,56].

Theme 4: The centrality of processes of patient enablement

A series of aspects that improved the participants' healthcare experiences have also been identified. For example, access to tailored information was valued because it enabled patients to better understand the circumstances around their disease, and act accordingly. Information exchange usually took place when the patient was "enabled" to engage in such activity, for example when a good relationship with the doctor, and a favourable organisational culture [46,49], allowed them to "ask and talk freely" [57 p4].

Whereas most of the participants wanted to know a variety of things, from illness progression, to possible illness trajectories, alternative treatments, and treatments' side effects, a minority did not want to receive too much information, as they considered knowledge to be a source of distress [42,58]. On the other hand, information helped the participants take decisions, manage their condition with awareness, and cope with the stigma associated with some health problems [59].

Participants also cherished a positive relationship with the staff, as it made them feel safe and comfortable. Such positive relationships were built on mutual respect, legitimization of their illness experience, friendliness, care, trust, empathy, emotional support, and openness. It was also characterised by the clinicians taking time to listen to what patients had to say, and patients being known or remembered by their doctors [60]. Being known not only made patients feel valued as individuals, but also saved them the work of repeating their medical histories to healthcare professionals that did not know them, or that did not read their medical records [61]. Furthermore, the participants believed that the opportunity to share their knowledge and experiences should be considered valuable from a clinical point of view. In fact, patients' accounts also hinted at a wish for clinicians to adopt more holistic approaches to their care, and to be seen as "a whole person" [22,40,62,63].

Finally, a good relationship with the doctor, though valuable in itself, was still instrumental to knowledge-building. Therefore, the clinician's competence and ability to understand and address the complexity of the participants' illnesses, and to refer them to community or specialist services when applicable, was considered to be complementary to a good relationship.

Simply being ''nice'', however, was not welcomed if ineffective: "All the doctors are very nice, but they don't take any notice…They don't do anything." [28]

In turn, knowledge-building was also considered to improve the patient-clinician relationship [64]. Still, whereas some patients are already enabled to be proactive agents in their own care because of many and varied circumstances (e.g., the way in which they have been socialised, education, and life experiences among others), others lack knowledge of their own condition, hence being prevented from engaging in effective decision-making and self-management [50]. For example, language issues (e.g., not speaking the local language fluently) could represent a barrier to patient enablement [33,54], as well as a low socio-economic status (SES) and low levels of health literacy [31,50].

Line of argument synthesis: Aspects of PCC that matter to people with long-term conditions

After identifying these four themes, we engaged in meta-ethnography's line of argument synthesis by listing the themes, along with their sub-themes, on a blank piece of paper. Then, we linked inter-related concepts by connecting and clustering them, hence creating a mind-map. Relationships drawn were informed by the authors' knowledge of the literature, but were mainly grounded in the data. An excerpt of the themes and sub-themes is presented in table 1.

Table 1. Themes and sub-themes. For each theme, only five sub-themes are presented.

Themes →	**Theme 1 – The battlefield**	**Theme 2 – The maze**	**Theme 3 – Personhood**	**Theme 4 – Enablement**
Sub-themes →	- Perceived power imbalance - Feelings of fear - Feelings of anger - Perception of fighting a battle - Clinician's negative attitudes …	- Difficulties identifying services - Difficulties accessing services - Difficulties getting information - Difficulties understanding information - Navigating the system …	- Patient feels dehumanised - Healthcare experience's impact on patient's self-worth - Patient's unique characteristics - Feelings of humiliation - Patient vs Person …	- Tailored information - Clear communication - Positive relationship (care, trust, etc.) - Listening to the patient -Knowledgeable and competent healthcare professional …

For example, "feeling cared for" and able to "trust the doctor" (theme 4) were considered to improve the relational aspect of someone's healthcare experience, because it made communication easier. On the contrary, when patients were afraid to speak freely, and did not feel safe (theme 1), it could result in the clinician being unaware of important information, hence being unable to offer proper care. Therefore, the "relationship domain" (which includes aspects of healthcare, such as trust, safety, respect, etc.) was identified as one of the components of person-centred carefrom the patient’s perspective.

This led to the development of two more domains (see Fig. 3): the “epistemic domain” (including information availability, tailored information, knowledge exchange and creation, etc.) and the “organisational domain” (including flexibility, continuity, timely appointments, etc.). However, we considered that some of the sub-themes had a boundary-spanning nature, laying at the interface between two domains. For example, listening skills fostered both relationship building (relationship domain) and knowledge sharing (epistemic domain), whereas the clinician’s access to patient information contributed to both continuity of care (organisational domain) and to the patient’s feeling of “being known” by the doctor (relationship domain). This indicates that the boundaries between these domains are not clearly defined, and that all the elements interact to contribute to the whole, with each aspect being necessary, but not sufficient, to the achievement of PCC.

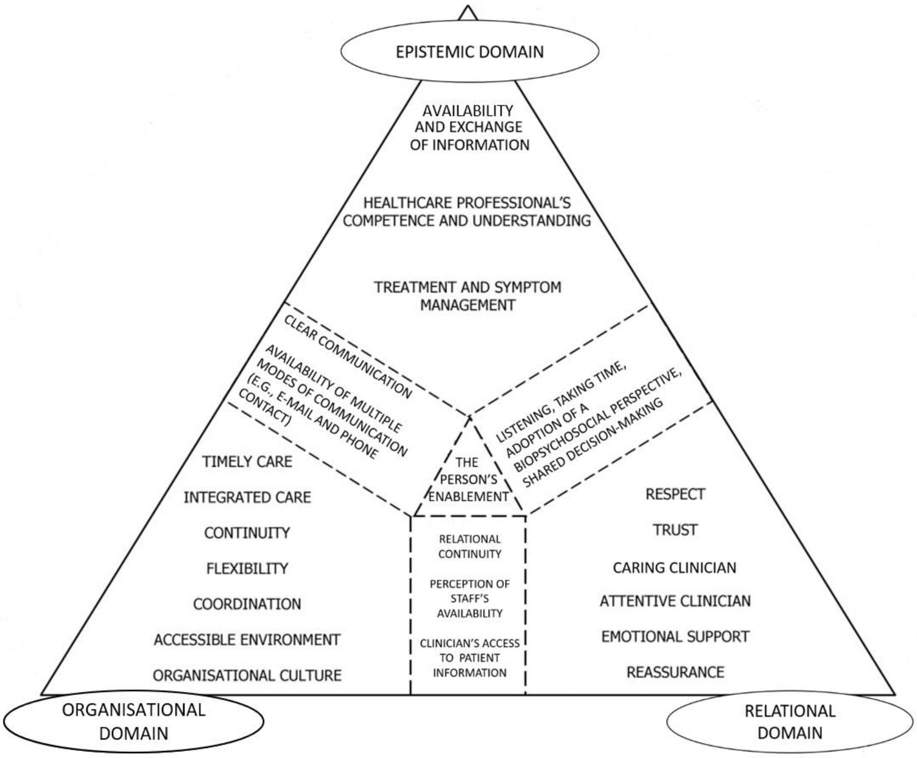

Figure 3. Diagram presenting the components of person-centred healthcare as described by the experiences of people with long-term conditions.

At the centre of this diagram is the person's enablement, as the patient/person inevitably interacts with all of these domains when attending healthcare services, but also needs to be enabled to engage with such domains proactively and successfully. It is important to specify that "enabling" is not a synonym of "helping", but refers to the achievement of a balance between offering help and respecting the patient's independence, which requires a cognitive effort, as well as, effective communication and sensitivity on the side of the practitioner [65], who has to adopt a flexible consultation style between (and sometimes within) consultations [66]. In fact, paternalism, under the guise of "too much help", was often contrasted by patients, and ended up contributing to the "battlefield" theme instead than to the "enablement" theme.

Discussion

As PCC is still not being achieved in practice, we set out to identify how people describe it, by interpreting their healthcare experiences through a PCC lens in order to consider whether a new understanding of PCC offers insight into why reported PCC is declining. According to this systematic review, the elements of PCC that matter to people with long-term conditions can be traced back to three main domains: epistemic, relational, and organisational.

As regards the epistemic domain, it is important to note that there is not just one form of knowledge. Russel Ackoff [67] was the first to posit a hierarchy of knowledge, at the top of which lay wisdom, followed by knowledge, information, and data. As Bernstein explained [68], the synthesis and compound of different types of knowledge (e.g., the patient's knowledge of illness experience, and the clinical knowledge of the doctor) can lead to wisdom that, according to Ackoff, is essential for the pursuit of valued goals. Yet, if a patient perceives the healthcare system as a battlefield, this has potentially negative implications for the achievement of wisdom, since knowledge sharing is supported by trust [69] and by a collaborative culture [70].

Actually, a positive relationship with the healthcare staff is important not only for knowledge-building purposes, but also because of the impact it has on the patient on a personal level. This systematic review showed that healthcare services can still cause unnecessary suffering to people [71], not just by contributing to their treatment burden [3,72], but also affecting them psychologically, with possible consequences being anxiety, hopelessness, and fear. Lian and Robson [22 p10] observed that “decades of debate and research emphasising person-centred clinical methods, [are] not traceable in the expressed experiences of … [the] study participants”. In this context, a further question should be raised, namely what is the extent (if any) to which such debates around PCC have been incorporated in the education curricula of medical students and healthcare professionals.

However, the achievement of a good relationship between the patient and the clinician needs to be enabled by organisational aspects of care, such as care coordination and integration, flexibility, and continuity. Some of these can be subsumed under the broader umbrella of the concept of access, previously defined as “the degree of "fit" between the clients and the system” [73 p128]. Access has also been defined in other ways, such as the potential to enter the healthcare system [74], or as people’s *ability* to obtain available health services [75]. The use of the term “ability” in the definition of access assumes an interesting meaning in the light of the fact that access seems to be one of the aspects of care that are usually beyond the patients’ control. Therefore, there might be a mismatch between what patients can do, and what the healthcare system assumes they can do. Over the last few years, research studies in the health sciences have acknowledged this mismatch, and found that people with long-term conditions nowadays deal with a significant workload, and need a certain capacity to do so [3,72].

At the “Centre” of Person-centred Care

Our synthesis shows that the doctor alone cannot achieve PCC. According to the experiences of the patients included in this systematic review, PCC is not something that can be delivered, provided, or administered (e.g., like a drug, or a rehabilitation technique). PCC is rather a process that can be achieved only collaboratively. Therefore, the challenge for the healthcare professional is not only that of understanding what kind of treatment the patient needs, but also that of enabling the patient to engage in a combined, collaborative effort in order to reduce, instead of increasing, the burden that they already carry [76]. The presence of organisational aspects in our diagram indicates that clinicians also need to be enabled to engage in person-centred clinical encounters, by the healthcare system organisational setup and, before then, by the very educational system that trains them to become healthcare professionals.

Yet, it seems that PCC is being increasingly reified by policies and guidelines, hence running the risk of reducing it to a checklist of behaviours, values, and principles that a healthcare provider has to follow – if they do, they can say that they deliver PCC. This is reflected by those cases in which some services guaranteed they offered PCC, whereas people using such services disagreed [52].

Comparison with other definitions of PCC

The findings of our systematic review are compatible with other definitions previously reported, such as that of Kitson and colleagues, who conducted a narrative review of the literature from health policy, medicine, and nursing in order to operationalise patient-centred care [77]. The elements of patient-centred care that they identified were (1) patient participation and involvement, (2) the relationship between the patient and the health professional, and (3) the context where care is delivered. Similarly, Scholl carried out a content analysis of 417 records, in an attempt to develop a conceptual definition of patient-centred care [78].

Kitson's and Scholl's definitions share both differences and similarities with our findings. For example, a positive relationship between the clinician and the patient has been found to be an important aspect of care by our systematic review, as well as by Kitson's and Scholl's reviews. However, compared to both, our review emphasised the importance that PCC should place on the patient's personhood. The idea of personhood is indeed acquiring increasing acknowledgement in studies around PCC, as it has been pointed out that primary care practice needs to be underpinned by theories of the self that could allow health professionals to understand the patient "as a self with intrinsic worth" [79 p135]. The fact that these aspects of care are not as emphasised in Kitson's and Scholl's reviews might be attributed to Scholl's analysis being based on a series of conceptual definitions of patient-centred care, Kitson's review being based on the views of different stakeholders (patients, policy makers, and professionals), and our review being based exclusively on patients' experiences.

Strengths and limitations

A strength of this review is that screening, data extraction, and quality appraisal were done independently by two authors on all the records. A limitation is that types of care such as telecare and home care were excluded from the review. However, this was done to keep the review as focused as possible, as there was a large number of studies about telecare and homecare, which could warrant a separate review.

Another strength is that we have updated our search prior to submission. The update resulted in five more papers being added to the systematic review. Still, although these papers contributed to the quality of the discussion by offering further insights to the interpretation of the studies, theoretical saturation (no emergence of new themes) was reached, hence the addition of the extra records did not change the findings significantly.

Also, this study allowed for the synthesis of the views of a large number of people, which is a strength as qualitative studies rarely involve high numbers of participants. However, along these lines, a limitation is that fifty-five studies might challenge the interpretative nature of a meta-ethnographic approach [80]. Yet, the use of meta-ethnography with a relatively large number of studies has been documented in several instances [19,81]. We addressed this challenge by considering the guidelines reported on methodological studies on the use of meta-ethnography with large numbers of studies [82], using a computer assisted analysis software to facilitate the synthesis, and dividing the studies in three groups instead of pooling them together, so that each group could be analysed in-depth.

Finally, it is important to note that this review focused on people's healthcare experiences, hence other relevant aspects that lay outside of the healthcare realm have not being identified, yet are part of what enables patients achieve PCC. Examples of such aspects are biographical reframing processes and realization of life work [83].

Conclusions

In its attempts to move closer to the patients, it could be suggested that the healthcare system has ended up moving away from them. However, this trend is not sustainable: today's patients have complex problems, and the disconnection between patients and healthcare services could end up increasing the workload for both patients and practices in the long-term. In fact, for an approach to be achieved and persist over time, it needs to make sense to the people involved [76], yet it seems that the way PCC has been implemented so far has not always made sense to the people who are supposed to be at its very centre.

We found that people with long-term conditions describe a person-centred healthcare system as one that values and respect their personhood, and enables them to build knowledge together with the clinician in order to manage their illness in a safe, caring, and accessible environment. Moving forward, further research might explain the relationships between the aspects of our diagram, or validate it through quantitative studies. Moreover, our systematic review suggests the need to review the direction of travel of PCC policies, interventions, and education, as the mismatch between patients' and other stakeholders' views around PCC might be partly attributed to differences in their views on what personhood is, and in the value and consideration that they attach to it. Therefore, it is important to engage in further theoretical reflection on the meaning of this concept in healthcare settings: how it is being defined, how it is impacted by healthcare experiences, and how (and if) it is being properly incorporated in current clinical practice and education. As policy and organisational changes take time [84], and the students that are starting medical school today will be doctors in ten years or more [85], it is important to act now, so that patients in the future have more opportunities to be enabled to become pro-active agents in the management of their long-term conditions.

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Appendix B – Meta-ethnography – Search strategies

The search strategies that I adopted for each database are reported below.

Medline

1. exp Primary Health Care/

2. exp GENERAL PRACTICE/

3. exp Secondary Care/

4. primary care.mp.

5. general practice.mp.

6. secondary care.mp.

7. community care.mp.

8. specialist care.mp.

9. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8

10. exp CHRONIC DISEASE/

11. exp MULTIPLE CHRONIC CONDITIONS/

12. exp Patients/

13. (long term and (disease* or illness* or condition* or disorder*)).ti,ab.

14. (chronic* and (disease* or ill* or condition* or disorder*)).ti,ab.

15. ((people or user* or patient*) and (long term or chronic*)).ti,ab.

16. 10 or 11 or 12 or 13 or 14 or 15

17. exp Patient-Centered Care/

18. (patient centered or person centered).mp.

19. (patient-centred or person centred).mp.

20. (patient centredness or person centredness).mp.

21. (patient centeredness or person centeredness).mp.

22. 17 or 18 or 19 or 20 or 21

23. exp “Delivery of Health Care”/

24. exp PUBLIC HEALTH PRACTICE/

25. exp Therapeutics/

26. ((healthcare or health) and (service* or practice* or setting*)).ab,ti.

27. (attend* or use* or treatment* or care* or cure*).ab,ti.

28. 23 or 24 or 25 or 26 or 27

29. (Experienc* or Perspective* or View* or Feedback* or Barrier* or Facilitat* or Perceiv* or Perception* or Impact* or Preference* or Attitude* or Challenge* or Meaning* or Consequence* or Opinion* or Report* or Belief*).ab,ti.

30. exp QUALITATIVE RESEARCH/

31. (qualitative* or mixed-method* or interview* or focus group* or narrative* or ethnograph* or phenomenolog* or grounded theory or hermeneutic* or emic or etic).mp

32. 29 or 30 or 31

33. 9 and 16 and 22 and 28 and 32

CINHAL (Cumulative Index to Nursing and Allied Health Literature)

S1 (MH “Primary Health Care”)

S2 (MH “Secondary Health Care”)

S3 primary care OR general practice OR secondary care OR community care OR specialist care

S4 S1 OR S2 OR S3

S5 (MH “Patients”)

S6 (MH “Chronic Disease”)

S7 AB (long term AND (disease* or illness* or condition* or disorder*)) OR (chronic* AND (disease* or ill* or condition* or disorder*)) OR ((people or user* or patient*) AND (long term or chronic*))

S8 (MH “Patient Centered Care”)

S9 (patient or person) cent?red*

S10 (MH “Health Care Delivery”)

S11 AB ((healthcare or health) and (service* or practice* or setting*)) OR (attend* or use* or treatment* or care* or cure*)

S12 AB (Experienc* or Perspective* or View* or Feedback* or Barrier* or Facilitat* or Perceiv* or Perception* or Impact* or Preference* or Attitude* or Challenge* or Meaning* or Consequence* or Opinion* or Report* or Belief*)

S13 (MH “Qualitative Studies”)

S14 qualitative* or mixed-method* or interview* or focus group* or narrative* or ethnograph* or phenomenolog* or grounded theory or hermeneutic* or emic or etic

S15 S5 OR S6 OR S7

S16 S8 OR S9

S17 S10 OR S11

S18 S12 OR S13 OR S14

S19 S4 AND S15 AND S16 AND S17 AND S18

Scopus and Web of Science (same search strategy)

1 – (primary AND care) OR (general AND practice) OR (secondary AND care) OR (community AND care) OR (specialist AND care)

2 – ABS ((long AND term AND (disease* OR illness* OR condition* OR disorder*)) OR (chronic* AND (disease* OR ill* OR condition* OR disorder*)) OR ((people OR user* OR patient*) AND (long AND term OR chronic*)))

3 – (patient OR person) cent?red*

4 – ABS (((healthcare OR health) AND (service* OR practice* OR setting*)) OR (attend* OR use* OR treatment* OR care* OR cure*))

5 – Qualitative* OR mixed-method* OR interview* OR focus AND group* OR narrative* OR ethnograph* OR phenomenolog* OR grounded AND theory OR hermeneutic* OR emic OR etic

6 – #1 and #2 and #3 and #4 and #5

PsycINFO

1. exp Primary Health Care/

2. exp Health Care Services/

3. Secondary Care.mp.

4. primary care.mp.

5. general practice.mp.

6. community care.mp.

7. specialist care.mp.

8. 1 or 2 or 3 or 4 or 5 or 6 or 7

9. exp Chronic Illness/

10. exp Comorbidity/

11. exp Patients/

12. (long term and (disease* or illness* or condition* or disorder*)).m_titl.

13. (chronic* and (disease* or ill* or condition* or disorder*)).m_titl.

14. ((people or user* or patient*) and (long term or chronic*)).m_titl.

15. 9 or 10 or 11 or 12 or 13 or 14

16. (patient centered or person centered).mp.

17. (patient-centred or person centred).mp.

18. (patient centredness or person centredness).mp.

19. (patient centeredness or person centeredness).mp.

20. 16 or 17 or 18 or 19

21. exp Health Care Delivery/

22. ((healthcare or health) and (service* or practice* or setting*)).m_titl.

23. (attend* or use* or treatment* or care* or cure*).m_titl.

24. 21 or 22 or 23

25. (Experienc* or Perspective* or View* or Feedback* or Barrier* or Facilitat* or Perceiv* or Perception* or Impact* or Preference* or Attitude* or Challenge* or Meaning* or Consequence* or Opinion* or Report* or Belief*).mp.

26. exp Qualitative Methods/

27. (qualitative* or mixed-method* or interview* or focus group* or narrative* or ethnograph* or phenomenolog* or grounded theory or hermeneutic* or emic or etic).mp.

28. 25 or 26 or 27

29. 8 and 15 and 20 and 24 and 28

ASSIA (Applied Social Sciences Index & Abstracts)

mainsubject.Exact(“chronic liver diseases” OR “primary care trusts” OR “chronic diseases” OR “chronic disease” OR “primary care” OR “chronic lung diseases” OR “chronic respiratory diseases” OR “qualitative research” OR “chronic obstructive pulmonary disease”)

AND

((primary AND care) OR (general AND practice) OR (secondary AND care) OR (community AND care) OR (specialist AND care))

AND

(ABS ((long AND term AND (disease* OR illness* OR condition* OR disorder*)) OR (chronic* AND (disease* OR ill* OR condition* OR disorder*)) OR ((people OR user* OR patient*) AND (long AND term OR chronic*))))

AND

((patient OR person) cent?red*)AND (((healthcare OR health) AND (service* OR practice* OR setting*)) OR (attend* OR use* OR treatment* OR care* OR cure*))

AND

(Qualitative* OR mixed-method* OR interview* OR focus AND group* OR narrative* OR ethnograph* OR phenomenolog* OR grounded AND theory OR hermeneutic* OR emic OR etic)

British Nursing Database (was “British Nursing Index” at the time of the search)

mainsubject.Exact(“primary care”)

AND

mainsubject.Exact(“chronic illnesses” OR “chronic illness” OR “primary care” OR “qualitative research” OR “delivery of health care”)

AND

mainsubject.Exact(“qualitative research”)

AND

((primary AND care) OR (general AND practice) OR (secondary AND care) OR (community AND care) OR (specialist AND care))

AND

ab(((long AND term AND (disease* OR illness* OR condition* OR disorder*)) OR (chronic* AND (disease* OR ill* OR condition* OR disorder*)) OR ((people OR user* OR patient*) AND (long AND term OR chronic*))))

AND

ab((((healthcare OR health) AND (service* OR practice* OR setting*)) OR (attend* OR use* OR treatment* OR care* OR cure*)))

AND

((patient OR person) cent?red*)

AND

(Qualitative* OR mixed-method* OR interview* OR focus AND group* OR narrative* OR ethnograph* OR phenomenolog* OR grounded AND theory OR hermeneutic* OR emic OR etic)

Embase

1. exp primary medical care/exp general practice/

2. secondary health care/

3. primary care.mp.

4. general practice.mp.

5. secondary care.mp.

6. community care.mp.

7. specialist care.mp.

8. 1 or 2 or 3 or 4 or 5 or 6 or 7

9. exp chronic disease/

10. exp multiple chronic conditions/

11. patient/

12. (long term and (disease* or illness* or condition* or disorder*)).m_titl.

13. (chronic* and (disease* or ill* or condition* or disorder*)).ti,ab.

14. ((people or user* or patient*) and (long term or chronic*)).ti,ab.

15. 9 or 10 or 11 or 12 or 13 or 14

16. (patient centered or person centered).mp.

17. (patient-centred or person centred).mp.

18. (patient centredness or person centredness).mp.

19. (patient centeredness or person centeredness).mp.

20. 16 or 17 or 18 or 19

21. health care delivery/

22. exp therapy/

23. ((healthcare or health) and (service* or practice* or setting*)).ab,ti.

24. (attend* or use* or treatment* or care* or cure*).ab,ti.

25. 21 or 22 or 23 or 24

26. (Experienc* or Perspective* or View* or Feedback* or Barrier* or Facilitat* or Perceiv* or Perception* or Impact* or Preference* or Attitude* or Challenge* or Meaning* or Consequence* or Opinion* or Report* or Belief*).ab,ti.

27. Qualitative research/

28. (qualitative* or mixed-method* or interview* or focus group* or narrative* or ethnograph* or phenomenolog* or grounded theory or hermeneutic* or emic or etic).mp.

29. 26 or 27 or 28

30. 8 and 15 and 20 and 25 and 29

Pubmed

1. (((((((Primary care[MeSH Major Topic]) OR General practice[MeSH Major Topic]) OR secondary care[MeSH Major Topic]) OR primary care) OR general practice) OR secondary care) OR community care) OR specialist care

2. (((((chronic disease[MeSH Major Topic]) OR multiple chronic conditions[MeSH Major Topic]) OR Patients[MeSH Major Topic]) OR ((long term[Title/Abstract] AND (disease*[Title/Abstract] OR illness*[Title/Abstract] OR condition*[Title/Abstract] OR disorder*))[Title/Abstract])) OR ((chronic*[Title/Abstract] AND (disease*[Title/Abstract] OR ill*[Title/Abstract] OR condition*[Title/Abstract] OR disorder*))[Title/Abstract])) OR (((people[Title/Abstract] OR user*[Title/Abstract] OR patient*)[Title/Abstract] AND (long term[Title/Abstract] OR chronic*))[Title/Abstract])

3. ((((patient-centered care[MeSH Major Topic]) OR ((patient centered or person centered))) OR ((patient-centred or person centred))) OR ((patient centredness or person centredness))) OR ((patient centeredness or person centeredness))

4. (((Delivery of Health Care[MeSH Major Topic]) OR PUBLIC HEALTH PRACTICE[MeSH Major Topic]) OR (((healthcare[Title/Abstract] OR health)[Title/Abstract] AND (service*[Title/Abstract] OR practice*[Title/Abstract] OR setting*))[Title/Abstract])) OR ((attend*[Title/Abstract] OR use*[Title/Abstract] OR treatment*[Title/Abstract] OR care*[Title/Abstract] OR cure*)[Title/Abstract])

5. qualitative research[MeSH Major Topic]

6. #1 and #2 and #3 and #4 and #5

Cochrane library

#1 MeSH descriptor: [Primary Health Care] explode all trees

#2 MeSH descriptor: [General Practice] explode all trees

#3 MeSH descriptor: [Secondary Care] explode all trees

#4 primary care

#5 general practice

#6 secondary care

#7 community care

#8 specialist care

#9 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8

#10 MeSH descriptor: [Chronic Disease] explode all trees

#11 MeSH descriptor: [Chronic Disease] explode all trees

#12 MeSH descriptor: [Multiple Chronic Conditions] explode all trees

#13 MeSH descriptor: [Patients] explode all trees

#14 (long term and (disease* or illness* or condition* or disorder*))

#15 (chronic* and (disease* or ill* or condition* or disorder*))

#16 ((people or user* or patient*) and (long term or chronic*))

#17 #10 or #11 or #12 or #13 or #14 or #15 or #16

#18 MeSH descriptor: [Patient-Centered Care] explode all trees

#19 MeSH descriptor: [Patient-Centered Care] explode all trees

#20 (patient centered or person centered)

#21 (patient-centred or person centred)

#22 (patient centredness or person centredness)

#23 (patient centeredness or person centeredness)

#24 #18 or #19 or #20 or #21 or #22 or #23

#25 MeSH descriptor: [Delivery of Health Care] explode all trees

#26 ((healthcare or health) and (service* or practice* or setting*))

#27 (attend* or use* or treatment* or care* or cure*)

#28 #25 or #26 or #27

#29 (Experienc* or Perspective* or View* or Feedback* or Barrier* or Facilitat* or Perceiv* or Perception* or Impact* or Preference* or Attitude* or Challenge* or Meaning* or Consequence* or Opinion* or Report* or Belief*)

#30 MeSH descriptor: [Qualitative Research] explode all trees

#31 (qualitative* or mixed-method* or interview* or focus group* or narrative* or ethnograph* or phenomenolog* or grounded theory or hermeneutic* or emic or etic)

#32 #29 or #30 or #31

#33 #9 and #17 and #24 and #28 and #32

Grey literature search

The search of grey literature was not as structured as that of scientific databases, as only free text search terms could be used. The free text search and the number of records identified are summarised in table B1. As WorldCat allowed for a slightly more advanced search (i.e., use of the asterisk as a wildcard), search terms for WorldCat were slightly different and are presented separately in table B2. Most search results were yielded by WorldCat.

Table B.1. Search terms and results for grey literature databases.

Search terms → **Databases**	**long term and patient centred**	**long term and person centred**	**chronic and patient centred**	**chronic and person centred**
GreyLit	1	5	16	9
Involve Libraries	2	1	2	181
Open Grey	5	3	7	2

Table B.2. Search terms and results for WorldCat.

Search terms →	**chronic long term conditions, disorders, illness, sickness, patient centred* person centred***	**"experience*", "patient centred*" or "person centred*"**
WorldCat	107	409

Appendix C – Meta-ethnography – Results of quality appraisal

The results of the quality appraisal applied to the records in my meta-ethnography are reported in the table below.

Table C.1. Joanna Briggs Institute (JBI) quality appraisal scores. Records marked with an asterisk (*) next to the record number have been included after the search update.

	Authors and year	**Title**	**JBI scores (out of 10)**
1	Johansson *et al*., 1996.	"I've been crying my way"—qualitative analysis of a group of female patients' consultation experiences	**YES: 7** NO: 1 UNCLEAR: 2 N/A: –
2	Gilmore and Hargie, 2000	Quality issues in the treatment of depression in general practice	**YES: 3** NO: 3 UNCLEAR: 4 N/A: –
3	Cott, 2004	Client-centred rehabilitation: client perspectives	**YES: 8** NO: 2 UNCLEAR: – N/A: –
4	Harding *et al*., 2005	"It Struck Me That They Didn't Understand Pain": The Specialist Pain Clinic Experience of Patients With Chronic Musculoskeletal Pain	**YES: 9** NO: 1 UNCLEAR: – N/A: –
5	Naithani *et al*., 2006	Patients' perceptions and experiences of continuity of care in diabetes.	**YES: 6** NO: 2 UNCLEAR: 2 N/A: –

6	Abdulhadi *et al*., 2007	Patient-provider interaction from the perspectives of type 2 diabetes patients in Muscat, Oman: a qualitative study	**YES: 9** NO: – UNCLEAR: 1 N/A: /
7	Saver *et al*., 2007	A qualitative study of depression in primary care: missed opportunities for diagnosis and education	**YES: 6** NO: 3 UNCLEAR: 1 N/A: –
8	Bayliss *et al*., 2008	Processes of care desired by elderly patients with multimorbidities	**YES: 5** NO: 3 UNCLEAR: 2 N/A: –
9	Cooper *et al*., 2008	Patient-centredness in physiotherapy from the perspective of the chronic low back pain patient.	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
10	Egeli *et al*., 2008	Patients' views: improving care for people with fibromyalgia	**YES: 7** NO: 3 UNCLEAR: – N/A: –
11	Wilkes *et al*., 2008	Clients with chronic and complex conditions: their experiences of community nursing services	**YES: 7** NO: 3 UNCLEAR: – N/A: –
12	White *et al*., 2009	Stroke patients' experience with the Australian health system: A qualitative study	**YES: 7** NO: 1 UNCLEAR: 2 N/A: –

13	Teh *et al*., 2009	Older People’s Experiences of Patient-Centered Treatment for Chronic Pain: A Qualitative Study	**YES: 8** NO: – UNCLEAR: 2 N/A: –
14	Upshur *et al*., 2010	They don’t want anything to do with you”: Patient views of primary care management of chronic pain.	**YES: 8** NO: 2 UNCLEAR: – N/A: –
15	Cocksedge *et al*., 2011	Holding relationships in primary care: a qualitative exploration of doctors’ and patients’ perceptions	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
16	Hartley *et al*., 2011	Experiences of attendance at a neuromuscular centre: perceptions of adults with neuromuscular disorders	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
17	Jowsey *et al*., 2011	Effective communication is crucial to self-management: the experiences of immigrants to Australia living with diabetes.	**YES: 7** NO: 1 UNCLEAR: 2 N/A: –
18	Nakrem *et al*., 2011	Residents’ experiences of interpersonal factors in nursing home care: a qualitative study	**YES: 8** NO: 1 UNCLEAR: 1 N/A: –
19	Raven *et al*., 2012	Vulnerable patients’ perceptions of health care quality and quality data.	**YES: 5** NO: 3 UNCLEAR: 2 N/A: –

20	Toles *et al.*, 2012	Transitions in care among older adults receiving long-term services and supports	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
21 *	Hancock *et al.*, 2012	‘If you listen to me properly, I feel good’: a qualitative examination of patient experiences of dietetic consultations	**YES: 8** NO: 2 UNCLEAR: – N/A: –
22	Bergman *et al.*, 2013	Contrasting tensions between patients and PCPs in chronic pain management: a qualitative study.	**YES: 6** NO: 2 UNCLEAR: 2 N/A: –
23	Cabassa *et al.*, 2014	Primary health care experiences of Hispanics with serious mental illness: a mixed-methods study.	**YES: 5** NO: 2 UNCLEAR: 3 N/A: –
24	Hudon *et al.*, 2013	Family physician enabling attitudes: a qualitative study of patient perceptions	**YES: 7** NO: 1 UNCLEAR: 2 N/A: –
25	Kuluski *et al.*, 2013	The care delivery experience of hospitalized patients with complex chronic disease	**YES: 7** NO: 1 UNCLEAR: 2 N/A: –
26	Morton *et al.*, 2013	Patients’ perspectives of long-term follow-up for localised cutaneous melanoma	**YES: 5** NO: 3 UNCLEAR: 2 N/A: –

27	Protheroe *et al*., 2013	'Permission to participate?' A qualitative study of participation in patients from differing socio-economic backgrounds.	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
28	Winsor *et al*., 2013	Experiences of patient-centredness with specialized community-based care: a systematic review and qualitative meta-synthesis.	**YES: 5*** NO: – UNCLEAR: 6 N/A: – ** out of 11 (JBI systematic review checklist)*
29	Clarke *et al*., 2014	"I Try and Smile, I Try and Be Cheery, I Try Not to Be Pushy. I Try to Say 'I'm Here for Help' but I Leave Feeling… Worried": A Qualitative Study of Perceptions of Interactions with Health Professionals by Community-Based Older Adults with Chronic Pain.	**YES: 8** NO: 1 UNCLEAR: 1 N/A: –
30	McMillan *et al*., 2014	How to attract them and keep them: the pharmacy attributes that matter to Australian residents with chronic conditions	**YES: 7** NO: – UNCLEAR: 3 N/A: –
31	Zimmermann *et al*., 2014	Patient perspectives of patient-centeredness in medical rehabilitation	**YES: 5** NO: 4 UNCLEAR: 1 N/A: –

32	Baudendistel *et al.*, 2015	Bridging the gap between patient needs and quality indicators: a qualitative study with chronic heart failure patients	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
33	Brown *et al.*, 2015	Exploring the patient and staff experience with the process of primary care.	**YES: 6** NO: 3 UNCLEAR: 1 N/A: –
34	Deslandes *et al.*, 2015	An exploratory study of the patient experience of pharmacist supplementary prescribing in a secondary care mental health setting.	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
35	Murphy *et al.*, 2015	A qualitative study of the experiences of care and motivation for effective self-management among diabetic and hypertensive patients attending public sector primary health care services in South Africa.	**YES: 7** NO: 1 UNCLEAR: 2 N/A: –
36	Östman *et al.*, 2015	Health-care encounters create both discontinuity and continuity in daily life when living with chronic heart failure – A grounded theory study	**YES: 9** NO: 1 UNCLEAR: – N/A: –
37	Sav *et al.*, 2015	The ideal healthcare: priorities of people with chronic conditions and their carers.	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
38	Sheridan *et al.*, 2015	Patients’ engagement in primary care: powerlessness and compounding jeopardy	**YES: 7** NO: 2

			UNCLEAR: 1 N/A: –
39	Donnelly and MacEntee, 2016	Care perceptions among residents of LTC facilities purporting to offer person-centred care	**YES: 8** NO: 1 UNCLEAR: 1 N/A: –
40	Nygren Zotterman *et al.*, 2016	Being in togetherness: meanings of encounters within primary healthcare setting for patients living with long-term illness	**YES: 10** NO: – UNCLEAR: – N/A: –
41	Wright *et al.*, 2016	Narratives of acquired brain injury patients: Their experience of healthcare relationships and medical decision-making	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
42	Benham-Hutchins *et al.*, 2017	"I want to know everything": a qualitative study of perspectives from patients with chronic diseases on sharing health information during hospitalization	**YES: 7** NO: 1 UNCLEAR: 2 N/A: –
43	Chiu *et al.*, 2017	Barriers to the Accessibility and Continuity of Health-Care Services in People with Multiple Sclerosis: A Literature Review	**YES: 5*** NO: 2 UNCLEAR: 4 N/A: – ** out of 11 (JBI systematic review checklist)*
44	Duthie *et al.*, 2017	Living with cancer and other chronic conditions: Patients' perceptions of their healthcare experience	**YES: 5** NO: 2

			UNCLEAR: 3 N/A: –
45	Harrison and Frampton, 2017	Resident-Centered Care in 10 US Nursing Homes: Residents' Perspectives.	**YES: 9** NO: 1 UNCLEAR: – N/A: –
46	Ho *et al*., 2017	It's a fight to get anything you need" – Accessing care in the community from the perspectives of people with multimorbidity	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
47	Lian and Robson, 2017	"It´ s incredible how much I've had to fight." Negotiating medical uncertainty in clinical encounters.	**YES: 4** NO: 3 UNCLEAR: 3 N/A: –
48	Melhem and Daneault, 2017	Needs of cancer patients in palliative care during medical visits: Qualitative study.	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
49	Zizzo *et al*., 2017	Examining chronic care patient preferences for involvement in health-care decision making: the case of Parkinson's disease patients in a patient-centred clinic.	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –
50	Dams-O'Connor *et al*., 2018	Patient perspectives on quality and access to healthcare after brain injury.	**YES: 7** NO: 2 UNCLEAR: 1 N/A: –

51*	Laitila *et al*., 2018	Service users' views regarding user involvement in mental health services: A qualitative study	**YES: 9** NO: - UNCLEAR: 1 N/A: –
52*	Morris *et al*., 2018	A qualitative examination of patients experiences of dietitians' consultation engagement styles within nephrology	**YES: 10** NO: – UNCLEAR: – N/A: –
53*	Fu *et al*., 2018	The management of chronic back pain in primary care settings: Exploring perceived facilitators and barriers to the development of patient-professional partnerships	**YES: 9** NO: 1 UNCLEAR: – N/A: –
54*	Chan *et al*., 2018	Patients' perceptions of their experiences with nurse-patient communication in oncology settings: A focused ethnographic study	**YES: 8** NO: 1 UNCLEAR: 1 N/A: –

Appendix C - References

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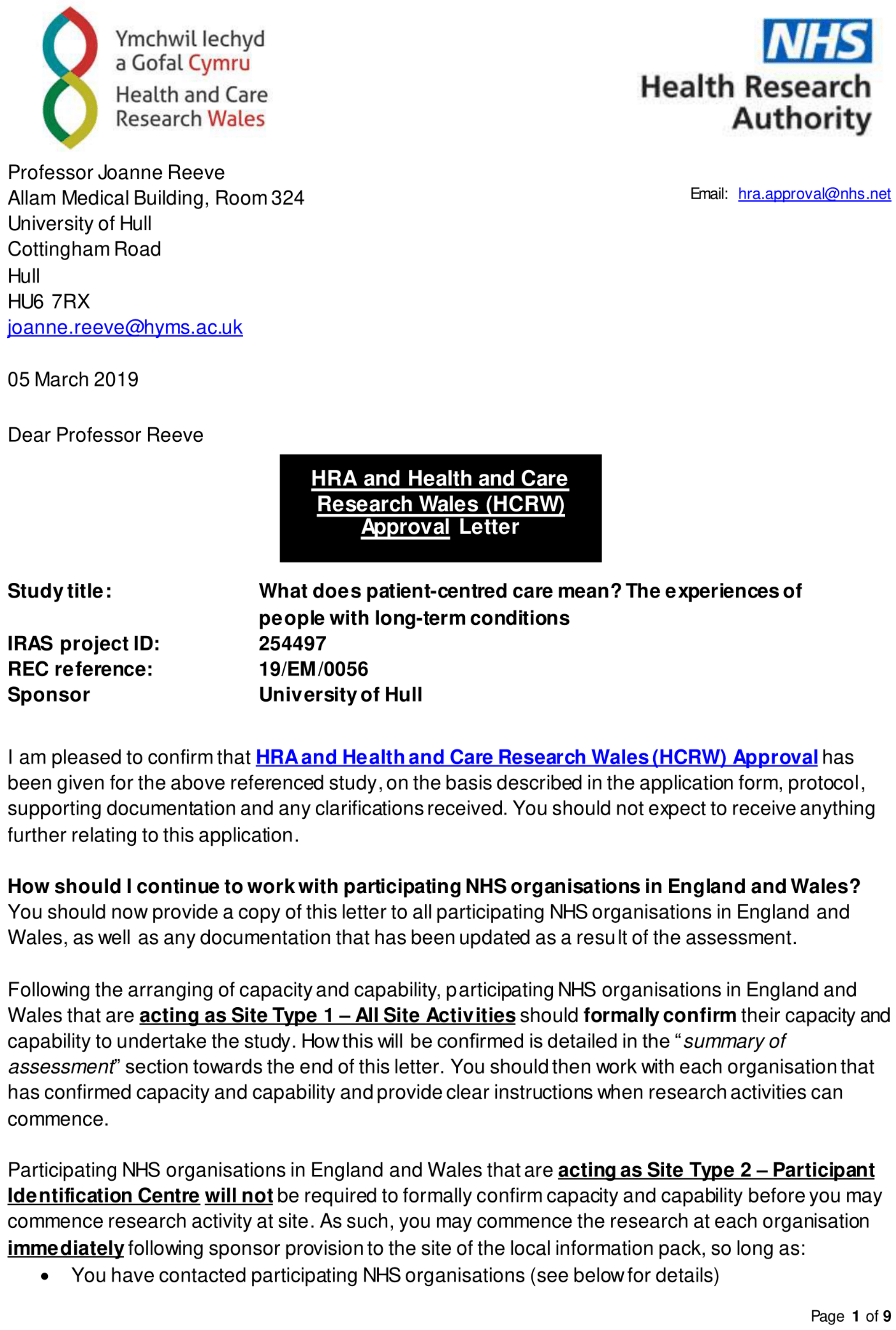
Appendix D – Evidence of ethical approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Professor Joanne Reeve
Allam Medical Building, Room 324
University of Hull
Cottingham Road
Hull
HU6 7RX
joanne.reeve@hyms.ac.uk

Email: hra.approval@nhs.net

05 March 2019

Dear Professor Reeve

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: **What does patient-centred care mean? The experiences of people with long-term conditions**
IRAS project ID: **254497**
REC reference: **19/EM/0056**
Sponsor **University of Hull**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations in England and Wales that are **acting as Site Type 1 – All Site Activities** should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter. You should then work with each organisation that has confirmed capacity and capability and provide clear instructions when research activities can commence.

Participating NHS organisations in England and Wales that are **acting as Site Type 2 – Participant Identification Centre will not** be required to formally confirm capacity and capability before you may commence research activity at site. As such, you may commence the research at each organisation **immediately** following sponsor provision to the site of the local information pack, so long as:

- You have contacted participating NHS organisations (see below for details)

- The NHS organisation has not provided a reason as to why they cannot participate
- The NHS organisation has not requested additional time to confirm.

You may start the research prior to the above deadline if the site positively confirms that the research may proceed.

If not already done so, you should now provide the local information pack for your study to your participating NHS organisations. A current list of R&D contacts is accessible at the NHS RD Forum website and these contacts MUST be used for this purpose. After entering your IRAS ID you will be able to access a password protected document (password: **Redhouse1**). The password is updated on a monthly basis so please obtain the relevant contact information as soon as possible; please do not hesitate to contact me should you encounter any issues.

Commencing research activities at any NHS organisation before providing them with the full local information pack and allowing them the agreed duration to opt-out, or to request additional time (unless you have received from their R&D department notification that you may commence), is a breach of the terms of HRA and HCRW Approval. Further information is provided in the "*summary of assessment*" section towards the end of this document.

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Andrew Taylor
Tel: 01482 463 806
Email: a.f.taylor@hull.ac.uk

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **254497.** Please quote this on all correspondence.

Yours sincerely

Gemma Oakes
Assessor

Email: hra.approval@nhs.net

Copy to: *Mr Andrew Taylor, University of Hull [Sponsor Contact]*
a.f.taylor@hull.ac.uk
Dr Marie Girdham, North Yorkshire and Humber CSU [Lead NHS R&D Contact]
marie.girdham@nhs.net

Appendix E – Advertising e-mails for recruitment purposes

Invitation letter/e-mail to primary care practices

Hull York Medical School
Academy of Primary Care
Allam Medical Building
Cottingham Road
HU6 7RX
Hull

Dear <<insert name of Practice Manager>>

The Academy of Primary Care (Hull York Medical School) is hosting a research project about the experiences of people with long-term conditions with patient-centred care in primary care settings. We define patient-centred care as care that is respectful and takes into account the needs and preferences of the patients, and that involves him or her in decision-making processes and by taking into account the illness experience as a whole. We are writing to you as we hope you will be interested in participating in the study, and to tell you more about it.

Studies conducted in the UK show that patients' satisfaction with patient-centred care is decreasing. However, people's voices have not been represented adequately, as they have usually been captured by surveys and questionnaires that failed to inquire into their personal experiences. In this study, we aim to understand what are the elements of patient-centred care that matter to people with long-term conditions by exploring their experiences with primary care services.

We are hoping that you could help us recruit participants for this project. In particular, we are looking for patients at your practice that are adults and have one or more long-term conditions, and would like to invite them to participate in a focus group and/or an interview.

We would greatly appreciate if you could facilitate the recruitment process, for example by displaying leaflets or hanging posters about this study in the premises of your practice, or if you could ask your staff to identify patients that meet the inclusion criteria and tell them about this study.

Please, feel free to reply to this e-mail <<*or letter*>> or to call us (phone number: <<insert number>>) if you are interested in collaborating and would like to receive further information. If you do, Myriam will arrange a meeting with you to provide you with further details and answer any questions you might have. <<*letter version: Alternatively, you can respond by using the enclosed Self Address Envelope*.>>

This study has received ethical approval by the NHS Research Ethics Committee <<*insert ref*.>>. We believe in the importance of this study as a way to improve the delivery of patient-centred primary care in the UK, and we hope that you will be interested in knowing more.

Thank you very much for taking the time to read this. We are looking forward to hearing from you.

With best regards,

Myriam Dell’Olio – PhD student
Prof. Joanne Reeve – Chief Investigator and academic supervisor
Dr. Julie Seymour – Academic supervisor

Invitation to local PPI, community, and patients' organisations

Hull York Medical School
Academy of Primary Care
Allam Medical Building
Cottingham Road
HU6 7RX
Hull

Dear <<insert name of group or of representative>>

The Academy of Primary Care (Hull York Medical School) is carrying out a research project about the experiences of people with long-term conditions with patient-centred care in primary care settings (e.g., GP surgeries). We define patient-centred care as care that is respectful and takes into account the needs and preferences of the patients, and that involves him or her in decision-making processes and by taking into account the illness experience as a whole. We are writing to you as we hope you will be interested in participating in the study, and to tell you more about it.

Studies conducted in the UK show that patients' satisfaction with patient-centred care is decreasing. However, people's voices have not been represented adequately, as they have usually been captured by surveys and questionnaires that failed to inquire into their personal experiences. In this study, we aim to understand what are the elements of patient-centred care that matter to people with long-term conditions by exploring their experiences with primary care services.

We are hoping that you could help us recruit participants for this project. In particular, we are looking for adults that have one or more long-term conditions, and would like to invite them to participate in focus groups and/or interviews.

We would greatly appreciate if you could facilitate the recruitment process, for example by displaying leaflets or hanging posters about this study in the premises of your organisations' location, or if you could identify any members of your organisation that match the description of the type of people we'd like to recruit and tell them about this study.

Please, feel free to reply to this e-mail <<*or letter*>> or to call us (phone number: <<insert number>>) if you are interested in collaborating and would like to receive further information. If you do, Myriam will arrange a meeting with you to provide you with further details and answer any questions you might have. <<*letter version: Alternatively, you can respond by using the enclosed Self Address Envelope*.>>

This study has received ethical approval by the NHS Research Ethics Committee <<*insert ref*.>>. We believe in the importance of this study as a way to improve the delivery of patient-centred primary care in the UK, and we hope that you will be interested in knowing more.

Thank you very much for taking the time to read this. We are looking forward to hearing from you.

With best regards,

Myriam Dell'Olio – PhD student
Prof. Joanne Reeve – Chief Investigator and academic supervisor
Dr. Julie Seymour – Academic supervisor

Letter to explain the study to potential recruiters (NHS practices)

Dear <<insert general practitioner/nurse>>

My name is Myriam and I am a PhD student at the Academy of Primary Care (Hull York Medical School). You are reading this letter because your practice has agreed to participate in a PhD project about the healthcare experiences of people with long-term conditions. I would like to ask you to help me recruit participants for my study so that I can involve them in focus groups and/or interviews.

I am interested in including a variety of people with different backgrounds and health conditions. In particular, I am looking for any of your patients that:

- are adults (aged 18 and above);
- have one or more long term condition;
- have the capacity to provide informed consent (e.g., do not have serious cognitive impairments);
- are able to speak English.

If any of your patients meets these requirements, I would greatly appreciate if you could tell them about this study, and give them an informative leaflet about it. If no leaflet has been provided to you, please ask the reception staff at your GP surgery for some. Alternatively, you can suggest the patient ask for a leaflet to the reception staff. If you need any further information, please feel free to contact me at <<insert e-mail address>> or <<insert phone number>>.

Thank you very much for your collaboration;

With Best regards,

Myriam

Letter to explain the study to potential recruiters (PPI groups or patients' organisations)

Dear <<insert person name>>

My name is Myriam and I am a PhD student at the Academy of Primary Care (Hull York Medical School). You are reading this letter because your organisation has agreed to collaborate to a PhD project about the healthcare experiences of people with long-term conditions. I would like to ask you to help me recruit participants for my study so that I can involve them in focus groups and/or interviews.

I am interested in including a variety of people with different backgrounds and health conditions. In particular, I am looking for people that:

- are adults (aged 18 and above);
- have one or more long term condition;
- have the capacity to provide informed consent (e.g., do not have serious cognitive impairments);
- are able to speak English.

If any of the members of your organisation meets these requirements, I would greatly appreciate if you could tell them about this study, and give them an informative leaflet about it. If you need any further information, please feel free to contact me at <<insert e-mail address>> or <<insert phone number>>.

Thank you very much for your collaboration;

With best regards,

Myriam

Appendix F – Individual interviews guide

The interview guide for the individual interviews is reported below. Arrows (→) indicate follow-up questions.

Welcome and introduction:

The interviewer introduces herself, the study aims, and reminds the interviewee about the ethical arrangements of the interview (e.g., the interviewee does not need to say anything that makes them uncomfortable, they can stop the interview or have a break whenever they want to, and so forth).

Interview questions:

1) Can you tell me how is it to leave with a long-term condition?
→ Has your life changed since then?

2) Can you describe your typical day at a GP surgery? From the moment in which you decide to schedule an appointment to the moment you leave the clinic. → Probing with examples (e.g., detailed description of the clinical encounter, scheduling appointment, etc.) and extensions (i.e., can you tell me more about that? What happened exactly?)

***3)** Think back to the times went to the GP. Do you remember a time in which you've left feeling particularly good? → What happened?
***3a)** Think back to the times went to the GP. Do you remember a time in which you've left feeling particularly bad? What happened?
→ How did that make you feel?
→ Have your feelings and thoughts changed since then? (Why?/How?)
→ What did you do (when things went wrong)? // Did you talk to anyone about this? (Who?)

* *If participant can't think of an example, ask about the last time they went to the GP, or about a memorable thing that happened when they went to the GP.*

4) If your experience had been different, do you think it would have made a difference? Why/how? [example: "if your doctor had/hadn't listened to you, do you think it would have made a difference?", "Why?", "How?"]

5) Managing a long-term condition is a complex job. What do you do to manage yours on a daily basis?
→ Why/what motivates you to manage your long-term condition?
→ Is there anyone who helps you manage it? (who and how/why)
→ Is there anyone, or anything, who you think could help you manage it better? (who and how/why)

6) Do you think GPs can help you manage your long-term conditions (or should they)?
→ Why?/How?

7) If you met someone today, with the same condition(s) and circumstances as you, and they asked you for advice - what advice would you give them?

8) Before we end the interview, there is one last question I would like to ask you. [Summarise briefly the main topics discussed so far]. So, based on your experience, what is person-centred care for you?

9) The interview is almost over. Is there anything you would like to add, or that you have liked me to ask you? Anything at all.

Conclusion

- Asking if there is anything about the interview that the participant would change or improve;
- Thanking the participant for their participation and stop recording/ending the interview.

Probing techniques examples: Clarification (can you explain…), extension (can you tell me more about…), evaluation (that's interesting/that must be challenging), intentional silence.

Appendix G – Focus groups guide

The interview guide for the focus groups is reported below. Arrows (→) indicate follow-up questions.

Welcome and introduction:

The interviewer and focus group assistant introduce themselves. The interviewer then gives an overview of the study aims. The participants will be told about the rules of a focus group (e.g., trying not to talk over each other, there are no right or wrong answers, participation is voluntary, and so forth.), and will be asked to introduce themselves (i.e., saying their names to facilitate the transcription).

Focus groups questions:

1) If you could rate your GP surgery using a traffic light, where "green" means great, "amber" means you're not sure, and "red" means bad, how would you rate it? (*ice-breaker question*)
→ Probe on the scores (e.g., "why green?").

2) Are there any things you like about the GP surgeries you are (or have been) registered to?
→ If yes, which ones and why? If not, why none?
2a) Are there any things you don't like?
→ If yes, which ones and why?

3) When you visit your GP surgery, do you think all of your needs are met?
→ Do you leave the practice feeling better?
→ Can you give me an example of when your needs were (not) met/you left the GP surgery feeling better/worse?

4) Do you think that going to the GP helps you manage your daily life?
→ If yes, how?
→ If not, why? (→ Should can they help more? Do you expect anyone else (who?) to do so?)

5) The interviewer introduces and reads a scenario in which the participants will pretend to be a GP:

Edith is 70 years old, she has several chronic diseases and is in persistent pain, as she has recently been to the hospital with a chest infection. The specialists have prescribed her some water tablets to relieve pressure on her heart, but she doesn't want to take them because she won't be able to leave her house for fear of needing the toilet. She fears that the hospital doctors didn't listen to her properly, and she is worried about losing her independence.

6a) Now, try to put yourself in Edith's shoes for a moment. Then, try to put yourself in her GP's shoes: If you were Edith's GP, what would you recommend she do about the water tablets?
6b) What do you think Edith's main problem is?
→ What would you suggest Edith does in order to deal with this problem?
→ Have you had the same or a similar issue before? → What did you do/how did you react?

7) Suppose that you were in charge and money wasn't an issue. You can make one change that would make general practice better. What would you do? Why?

8) We have discussed for some time now about primary care and its characteristics. Now, I would like to ask you one final thing: What is patient (or person) -centred care to you? (If you could define it, how would you define it?)

9) The interview is almost over. Is there anything you would like to add, or that you have wanted me to ask you? Any final comments you would like to make? (Making rounds – checking with each participant)

Wrapping up

- Summarizing the main points of the discussion;

- Asking if there is anything about the focus group process that the participants enjoyed or that needs improving;
- Thanking the members of the focus group for their participation and stop recording/ending the interview.

Probing techniques: Clarification (can you explain…), extension (can you tell me more about/can you give me an example…), evaluation (that is unexpected/that must be challenging), intentional silence; exploring strong agreement or disagreement between the members, or strong feelings associated with one specific topic.

Appendix H – Interpretive Phenomenological Analysis: A description of the process

In this appendix, I provide a detailed description of the analysis process for the individual interviews, and explain how I applied interpretative phenomenological analysis (IPA) to develop the findings of my thesis.

H.1 Data collection

During each interview, I took field notes, which included both demographic characteristics and comments about the participants' answers. Whereas most notes were contextual, others were more interpretative.

Example of a contextual note (personal details have been anonymised):

> "[Oliver] speaks in short sentences because of breathlessness /His long pauses are due to the need to catch breath / He has short-term memory issues, probably affecting some answers to my questions, in particular when he's talked for a while."

Example of an interpretative note (personal details have been anonymised):

> [Angela] says she's blessed with good health even though she has [an endocrine condition]. She speaks a lot about [her sleep disorder] and barely mentions [the other condition] / [the other condition] is overshadowed by [the sleep disorder].

After conducting the first two interviews, I shared the transcript of the first interview with my supervisors (Prof. Joanne Reeve and Dr. Julie Seymour) to comment on the quality and richness of the data that I was collecting.

H.2 Starting the analysis

After conducting the third interview, I started the data analysis process following the guidelines suggested by Smith (1999) for conducting IPA with a relatively large number of transcripts. First, I transferred each transcript on a dedicated NVivo library (NVivo 12, QSR International). I familiarised with the transcripts by reading them and writing down comments using the "annotations" function on NVivo. I also integrated each transcript with any field notes at this stage. Annotations included reflections, thoughts about other transcripts, or contradictions that I noticed within the transcript and that I wanted to explore further. I started coding after familiarising with the first three transcripts.

H.3 Clustering similar topics

I started coding bigger chunks of text (e.g., parts of a sentence, sentences, or even small paragraphs). Coding mainly involved descriptive codes, with some interpretative codes, because my aim at this stage was that of identifying organisational categories (McMillan and Schumacher, 2001), namely the main topics described by each participant, which work as "bins for sorting the data for further analysis" (Maxwell, 2008, p. 237). I provide an example below, through Mary's account of how her illness impacted her life.

Table H.1. Coding Mary's transcript. Text and corresponding codes are highlighted and formatted in the same way.

Excerpt	**Codes**
Mary: *That's how it's impacted on our lives, but we haven't let it, really, in our lives*, we've got through it, and we're through it now, cos my husband's 76, so we're getting into that age bracket where the family are trying to look after us, I think. And we were a bit stubborn you know, they say "why didn't you ring, we could have come pick you up" – and I go: "well, because we could go [to the doctor] on a bus!" So you've got to keep your independence, even if you're getting older.	*Fighting illness* Journey Sense-making Persistence Family support Awareness of own resources Independence

This process was inductive, as it did not draw on any a priori framework or coding index. In the example above, I coded parts of the text mostly in a descriptive way (though I occasionally used more latent codes such as "fighting illness" or "journey"), to start identifying the topics and areas described by the participants' experiences. After coding each transcript, I developed a coding summary. In line with the previous example, I'm including a coding summary for Mary's transcript in the table below.

Table H.2. Coding summary of Mary's transcript.

Category	Codes (and notes)
Impact of long-term condition	Forced change Changing role (family) Cherished activities taken away Compromise Fighting against the illness Illness as a journey Sense of uncertainty
Impact of treatment	Medication as a burden Sense of liberation (when reducing medication to bare necessities) The lesser evil (no good choice available) Side effects
Cognitive processes (to deal with a long-term condition)	Awareness of own limits Awareness of own resources Learning through experience (Wait and see, try and see) Reflecting on symptoms' meaning Sense-making Selective focus (on the positive aspects of new lifestyle/optimism)
Resources for health	Family support Persistence Agency Network Sense of safety Carers' understanding

Table H.2 (Continuation). Coding summary of Mary’s transcript.

Category	Codes (and notes)
Perceived characteristics of general practice	GP as source of resources GP’s competence General practice as alien [in vivo code] Reminder function (reminds participant she has an illness) Uncertainty about the GP’s role Abandoned by doctors [Feeling] Dehumanised Being taken seriously Unprofessional language Access Coordination of care Timing of care
Personal aims	Sense of control (over illness) Preservation (“I don’t want [to get worse], I just want to be as I am”) Definition of health (there's more to life than illness) Independence “Get it sorted” [in vivo code]

As can be seen from the table above, I kept the main categories broad, to allow for the following stage in which I had to identify topics discussed across all transcripts. For example, other participants also talked about personal aims or characteristics of general practice, but from their own perspective. This helped me get an idea about the various nuances of each category across my dataset.

I put the coding summaries together by looking at the main categories first. I merged similar sub-categories into bigger categories where applicable. For example, I put together the categories “impact of treatment” and “impact of long-term condition” from the table above to form a bigger category (i.e., topic), "living with a long-term condition". Through this process, I identified three main topics covered by the interviews:

1) Primary care experiences
2) Living with a long-term condition
3) Self-management

Within each topic there were several sub-topics. For example, "Inevitable change" was a sub-topic of "Living with a long-term condition". As different participants talked about inevitable change in different ways, the topic area of "Inevitable change" was further divided into sub-categories, including "changing role", "changing difficulties", "things stripped away", "sense of identity", and "navigating between new and old normal". Similarly, the topic "Perspectives on primary care" included sub-categories like "access features", "healthcare professionals features", "patients' features", and "roles of primary care".

H.4 Identifying a topic to analyse through in-depth analysis

At this point, I needed to identify a topic for further, in-depth analysis. As I completed my systematic review, I based my decision on its findings.

The systematic review indicated that the most important aspects of person-centred care from a patient perspective were epistemic, relational, and organisational, and that person-centred care can only be achieved collaboratively. Therefore, I decided to explore instances of such collaborative effort, and to focus my in-depth analysis of the interview data on the participants' experiences of their clinical encounters and their communication with their doctors. This topic was part of the "Primary care experiences" cluster. I also expected that exploring such topic could help shed light on both epistemic and relational aspects of care (and, occasionally, on organisational aspects of care, which were explored more during the focus group interviews). Furthermore, in order to gain a deeper understanding of the knowledge work involved in the participants' healthcare experiences, I also collected excerpts about the participants' accounts of how they managed their long-term conditions.

At this point, I went back to the transcripts and identified all instances of communication between the participants and healthcare professionals, as well as their experiences managing their long-term conditions. I copied and pasted such instances on a new document in which all the excerpts were collated (though still divided by participant). Then, I proceeded to the next phase.

H.5 In-depth analysis: From description to interpretation

At this point of the analysis, I wanted to understand and interpret the participants' experiences of their clinical encounters and self-management practices. I did this by coding excerpts anew. I coded the excerpts in-depth, printing the document and using the left margin of each page to note down annotations, hunches and comments, and the right margin of the page to code pieces of text that I deemed meaningful or rich based on the study aims. I included an example of the case of Mark in the table below, who was telling me about his reluctance to ask his GP to review his medication.

Table H.3. Coding Mark's excerpts. Underlined text does not represent participant's emphasis, but my own highlights for analysis purposes.

Notes	**Excerpt**	**Codes**
	I: _Have you thought about telling your GP [that you think you take too many medicines]?_	
* No action from doctor → everything's fine _* Not sure about what the doctor did_	Mark: No, I won't. He said he did look at it, I think he looked at it when I went before, he sort of looked at it and doesn't do anything about it.	Apparent trust; uncertainty Sense-making
	I: _So you think he's fine with it, but you're not?_	
* Contradiction _* Learning through comparison with others_ _* Imperative ("come off that")_ _* Did not reach his goal (meds replaced, not reduced)_ _* Learning through checking bodily function_	Mark: Well, I mean… I'm not worried about it… I just think that… should someone review it? You know, I've watched different programmes where they talk about getting people off those medications, and… I had this Baclofen, which is a muscle relaxant, I took that, and the physio thought "that would be making you tired, so come off that", so the doctor agreed with that. Hum, but then I have Botox injections instead, which – probably every three months – which I don't know exactly how much benefit I get from them, I think it has gradually loosened up these fingers.	Uncertainty Learning; Initiative Sense-making (comparison) Awareness (knowledge) Clinician's initiative Different goals Uncertainty; Sense-making (Questioning, observation); Own explanation

Since coding was denser and more reflexive than in the previous phase, I proceeded to write a narrative coding summary of each set of excerpts, to facilitate the identification of preliminary themes within each account. I provide an excerpt from Mark's coding summary below.

> **Mark, 50s, neurological condition, multiple long-term conditions**
>
> In Mark's account, the doctor focuses on what matters to him/her rather than on what matters to Mark. When this happened, Mark's attitude can be seen as passive, as he does not ask a lot of questions, but rather goes with the doctor's agenda. However, the analysis actually shows that Mark does not trust completely the healthcare system and does not act passively in the context of managing his long-term condition, where he actively seeks information and observes carefully his own symptoms while pursuing an active life and goals.
>
> Upon recalling a positive healthcare experience, Mark says he felt better because he "had the answers". His worry was caused by some unanswered questions about the nature of his lumps. Positive primary care experiences for Mark are usually associated with relief of worry or getting answers to his questions about signs and symptoms that he could not explain himself. More specifically, positives include the doctor's readily available knowledge ("he knew straight away") and competence about symptoms' causes. For example, Mark said that the doctor knew straight away whereas he didn't – so he compared himself to the doctor in this instance, hence asserting the role of doctors from his perspective (to get him where he cannot get to on his own – e.g., an explanation).
>
> Mark reports a lack of a personal approach in his practice and says that the doctor forgot that he had already visited him before. He adds that the healthcare staff also seems to not know him. Yet, he justifies/rationalises the matter, keeping his criticism focused on the lack of answers to his questions.

As in the example above, I underlined the concepts and aspects that I deemed to be the most thematically rich because they described or explained concepts that were relevant to both the participant and the research questions (e.g., Mark's knowledge work of looking for an explanation to both his symptoms and treatment). Writing these narrative thematic summaries also helped me keep the idiographic focus of IPA, by locating and interpreting the emerging themes in the context of each participant's individual story. After doing this for each set of excerpts, I set out to identify the shared aspects of the participants experiences (i.e., recurring themes across the summaries) and used them to define some preliminary themes, which were the following:

- Characteristics of the clinical encounter
- Doctor lacks knowledge
- Clinician pursuing knowledge
- Patient's needs
- Staff's communication style
- Patient knowledge
- Self-management: motivation
- The practice around the encounter

Each of these preliminary themes had sub-themes that further explained or described their characteristics. I transferred all these themes, with their corresponding quotes, on a new document.

At this point, as the themes were still quite broad and descriptive in nature, I refined them by coding the quotes on the new document, and noting down reflections on the side. This was the first stage in which I engaged in an explicit cross-comparison of similar experiences (quotes) across different participants, allowing me to identify more nuances of the same experience. Taking "listening" as an example, whereas some participants emphasised how important it was for the doctor to listen to them because they believed they could share relevant information, others emphasised the aspect of "sitting" while listening, thus creating an atmosphere that would encourage the patient to talk, while someone else talked about how being listened to by their doctor helped them reflect on their illness.

This new process of coding led me to develop a more refined list of themes, whose focus was gradually narrowing on the actual processes guiding the person-centred clinical consultation. These preliminary themes were the following:

The person-centred insight
  Eliciting information
  Listening and integration
  Explaining information.

Challenges to knowledge building
  Doctor's perceived inquiring attitude
  System level barriers

A journey through knowledge
  Learning by exploring
  Navigating uncertainty

The work that followed consisted in further re-coding, re-describing and re-interpretating the data to explain more clearly the definitions and relationships between the various themes, and to describe more explicitly the actual processes that facilitate knowledge work during the clinical consultation. This was a long process of going back and forth between the data (quotes and transcripts), writing down my interpretations in the form of thesis chapters, and sharing my thoughts with my supervisors Prof. Joanne Reeve and Dr. Paul Whybrow.

This process revealed unsupported assumptions that required refining the analysis. For example, at this stage, I was looking for what made clinical encounters "person-centred". I realised that some key themes (e.g., "the person-centred insight", which I defined as the way in which the practitioner gains knowledge about the patient and the condition) were doctor-focused, hence were not giving me any insights in the patient's actual knowledge work during the clinical encounter. I identified "eliciting", "explaining" and "listening" as sub-themes of the person-centred insight, but I noticed that they were not inherently person-centred, as each of them could be more or less person-centred.

I believed that my themes at this stage had not captured the aspects of a person-centred clinical consultation yet. I revisited the excerpts to find both positive and negative examples of the participants' experiences with moments of eliciting information, listening and integration, and explanations, and decided to compare them to see what was making the difference between positive and negative experiences. I thus shifted my analysis on what the participants were doing, or achieving (i.e., their actual 'lived' experiences), during those moments. For example, moments of "explaining information" were more positive when the doctor explored multiple treatment options while asking for the patient's opinion, and more negative when the doctor did not justify their opinion to the patient. In these examples, as the GP was 'explaining' something, the participants were critically assessing the information s/he was providing. Therefore, whereas I initially framed "explaining information" as a doctor-focused moment, shifting the attention to the participant's lived experience allowed me to identify and explore the participant's knowledge work in that moment. I thus put the "person-centred insight" theme aside, and started developing the theme of the clinical negotiation with knowledge, which I felt captured the knowledge work of both doctor and patient during the clinical consultation as experienced by the participants.

As described in Chapter 3, I planned to integrate interview and focus groups data to see if and how they could complement each other. For example, the focus groups data also included instances of negotiations taking place during clinical encounters, in the form of actual experiences as well as opinions and beliefs. I described the process of data integration in the Methodology Chapter (see § 3.2.5, page 85).

Appendix H – References

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Glossary

Term	Definition
Aphasia	The inability to comprehend and/or produce language (oral and/or written). It can be characterised by various degrees of impairment.
Chest infection	An infection that affects the lungs and/or the lower airways.
Cortisol	One of the hormones produced by the adrenal glands (i.e., small glands that produce hormones and are located on top of both kidneys).
Emergency antibiotics	Informal expression used by the study participants to refer to antibiotics prescribed preventively on the off chance of an emergency (so not for immediate use).
Endocrine condition	Long-term condition that affects the endocrine system, which consists in a series of glands that produce and secrete hormones.
Gastroprotective drug	A type of drug that is used to protect the stomach lining from damage.
Long-term condition	Any continuing health condition or recurring for a long time. Also referred to as chronic condition.
Neuromuscular condition	Long-term condition that affects the nerves that control the muscles.
Neurological condition	Long-term condition that affects the nervous system (e.g., the brain, spinal cord and/or the nerves).
Patient Participation Group	In the context of a primary care practice, a group of patients, staff and carers that meet to discuss service issues and patient experience.
Patient support group	A group of people with a common experience with one or more long-term conditions, who meet regularly to support each other and raise awareness of the condition.

Pulmonary embolism	A condition that occurs when a blood clot causes a blockage of a blood vessel in the lungs.
Ranitidine	Gastroprotective drug (see glossary).
Respiratory condition	Long-term condition that affects the respiratory system (e.g., airways and/or lungs).
Steroids	A type of anti-inflammatory medicines.